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Many thanks.

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Name: Ashish Macaden

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SUSTAINING EMPLOYMENT

AFTER SUPPORTED EMPLOYMENT

IN ADULTS WITH ACQUIRED BRAIN INJURY

A thesis submitted in partial fulfilment of the requirements of
Northumbria University
for the degree of Doctor of Philosophy
in collaboration with Hunters Moor Regional Neurological Rehabilitation Centre
and
Rehab UK Tyne & Wear Brain Injury Centre.

ASHISH STEPHEN MACADEN

December 2004

ABSTRACT

SUSTAINING EMPLOYMENT AFTER SUPPORTED EMPLOYMENT IN ADULTS WITH ACQUIRED BRAIN INJURY

Modern Vocational Rehabilitation Programmes support individuals with Acquired Brain Injury (ABI) by using Job coaches who provide support both in placements and employment. This has improved return to work to around 70% compared to around 20 - 50% previously. But the reasons for success of this supportive process are not clear. Quantitative studies have attempted to correlate factors associated with employment, but results have been variable and conflicting. Long term data regarding sustaining employment is sparse. An exploratory study reported that around 26% of those who return to work could not sustain employment. Job coaches reported that this occurred because of dysfunctional interpersonal relationships (misinterpretation of social cues, interpersonal conflict and inappropriate verbalization), substance abuse, criminal activity, poor employment settings and economic disincentives. This study was built on the exploratory data and examined the area of sustaining employment in detail with the aim of developing a conceptual model.

A flexible, eclectic design based on multiple case studies was used.. Eight individuals with ABI were purposively selected along with a family member, employer or co-worker and job coach. Triangulation, respondent validation, peer debriefing and reflexivity were used to reduce bias and improve validity. Twenty nine semi-structured interviews were conducted. Transcripts were analysed for topics which were directly linked to sustained employment. Ideas which were directly associated by text were extracted. These concepts were used to develop a conceptual model.

Bio-psychological concepts which helped to sustain employment emerged from the research. This included the beneficial use of unconditional motivation, coping skills and pre-injury work and leisure interests. Pre-injury interests also demonstrably improved motivation.

S*ocial concepts* re-emphasised support from the employer or co-worker, support from the vocational rehabilitation programme and from the work place. An opt-out follow up pattern was proposed i.e. follow up is continued until individuals with ABI choose to opt out. The conceptual model proposes a cyclical continuum rather than a staged and linear approach. It advocates a greater role for employers and co-workers (pre and post-injury) in the process of employment.

The conceptual model challenges current practice: it recommends assessments of bio-psychological factors. It advocates greater integration at all levels. It also opens out research challenges in the areas of development of assessment tools for bio-psychological factors, comparison with services available for the unemployed in the general population and transferability of these findings to other projects and similar situations in ABI rehabilitation. It challenges current perceptions by demonstrating that individuals with ABI can be outstanding employees.

SUSTAINING EMPLOYMENT

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IN ADULTS WITH ACQUIRED BRAIN INJURY

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ACKNOWLEDGEMENT

This piece of research would not have been possible without the support of my supervisors, Colin and Barbara Chandler, who were not only a source of encouragement and support, but were also enablers.

I am indebted to Alister Berry whose experience and practical insights into vocational rehabilitation have been an invaluable source of reflection in the research process. I would also like to acknowledge the staff and clients at Rehab UK and their family members and work colleagues whose enthusiasm and forbearance have resulted in an invaluable contribution of rich data.

Professor Michael Barnes, Tina Cook and my colleagues in Hunters Moor never failed to encourage and support me both in word and deed. I was given ample time and opportunity to help me complete this piece of research. I am grateful for the blessing of consultants and work colleagues who constantly affirmed and reminded me that research was as important as clinical work.

I owe thanks in particular to my wife, Leah and my son, Mithran, who have been my faithful supporters, bearing with my invasions of their time and space with love and equanimity, and my father who sacrificed a holiday with us to proof read my manuscript.

Finally I thank God for all the blessings and miracles that have made this work possible.

DECLARATION

I declare that this work has not been submitted for any other award and that it is my work.

Ashish Stephen Macaden

CHAPTER 1

INTRODUCTION

Work is the grand cure of all the maladies and miseries that ever beset mankind

Thomas Carlyle (1795-1881)

This chapter introduces the reader to the background and development of this research project, the clinical environment that is experienced by an individual with acquired brain injury (**ABI**) and the vocational rehabilitation programmes that are available to them.

INTRODUCTION TO THE RESEARCH PROJECT

Context of Research

People with brain injury pose an increasingly immense challenge to rehabilitation teams all around the world. The two commonest causes of brain injury – trauma (often relating to road traffic accidents) and cerebro-vascular disease (often relating to hypertension) are inexorably becoming major international threats to health. Individuals with brain injury and their families, though often greatly affected, find themselves ignored or misunderstood. These issues are represented very well in a letter published by a brain injury association called Headway (Powell 1994), entitled "The Lucky One". It was written by a father whose 19 year old son had brain injury:

"To whom it may concern

Our plea to the medical world is that although you see us as the lucky ones we still need help and understanding. You see, it does not feel lucky to have a head injury or to have a relative who has one. We appreciate that many people die or have serious brain damage as a result of road accidents but our experience is of one of "the lucky ones" who needs understanding and guidance. – the things which we have found generally lacking..

To family and friends we would say that, although outwardly "the lucky one" appears well, inside so much is wrong. Understanding, love, time, patience and gentle encouragement are all needed in large measures.

"The lucky one" does not feel lucky, nor does the family hit by shock struggling to look after him. Confusion, sadness and desperation are all felt by "the lucky one" who feels different from the way he felt before the accident but does not know why. The family is also confused, frightened and unsure how to help.

Life for the injured is harder than usual – a real struggle, in fact. As he tries to sort out his thoughts agonisingly slowly, and remembering even little day to day things is

sometimes impossible. But he looks so normal that no one understands or seems to care. He is expected to act and think the way he did before the accident but he just can't. On top of that he feels so utterly exhausted. Everything is such hard work. Due to the confusion and inability to cope, friends shy away until he is left on his own. He longs for their understanding but he looks so normal and when he says he is having trouble with his memory, people reply " So do I, I am always forgetting things", or if he says he is exhausted, he receives the reply, " Oh yes, I feel tired all the time too. " But its different for the head injured who eventually says nothing about his memory or exhaustion and retreats into himself. Of course, his injury does not show like a broken leg in plaster – people make allowances for anyone in that condition. He is not seeking sympathy or pity, only understanding, or at least some attempt to understand so that people might realise why he acts the way he does. He can't put into words the way he feels, but he knows he does not feel right. He is afraid of being left alone in case he can't cope, he panics in crowds and is afraid to travel on the road – after all it was a road traffic accident that made him feel the way he does; but to the world he is a "lucky one".

He finds new tasks difficult to accomplish. He remembers things learnt before the accident but learning new things and remembering things he is told is virtually impossible. Likewise, making decisions, even simple ones is an insurmountable task. He can't explain why these things appear so difficult for him, but people do not understand because he looks so normal.

To the member of the nursing staff who gets cross with a head injured patient when he does something he has been told not to do, or forgets to do something he was told to do, we say "Please don't get cross, the patient really can't help it and he needs your understanding."

To the doctors who say he will be back to normal in a few weeks and should be able to return to work then, we say, "Please find out more about how head injuries affect patients, and the time it can take to recover, even partially, from those injuries." Families of the injured hang on to every work spoken by a doctor. After all he or she is expected to have some knowledge of how the injuries might affect the patient, so it is very important that doctors choose their words carefully, do not build up false

hopes for the family, and do not make statements that with hindsight even the layman can see are very misleading.

We would also ask the medical world, "Where is the post hospitalization care?" as in our experience, the patient is sent out from hospital and expected to cope on his own. His only link with anyone "medical" is his GP who, with the best will in the world is unable to offer any help other than to see the patient and ask rudimentary questions without providing any answers or details of where assistance might be sought. Bearing in mind the number of head injuries which occur annually, we were surprised that there appeared to be no one to turn to for help; at least, if there was, then neither the hospital nor the GP was aware of such a person or organization.

Our son returned to work, but even now, only part-time, and when his job was changed he felt he could not cope. That situation has still not been resolved yet.

It has been two years now and our son is still not one hundred percent well; the last two years have been a nightmare for the whole family and we are not through it yet. If only we had known more about what to expect and how to cope when our son was discharged from hospital. It has been a shock and a frightening experience for us all. Our daughter was diagnosed as suffering from post-traumatic stress and was put in touch with a social worker who involved the whole family and, through his sympathetic activity, was able to help us all.

Six months ago we at last found a professional interested in head injury, although he worked in the neighbouring health district. It was a relief and a tremendous help to find someone who know how we all felt. The Head way publications he offered us were also greatly reassuring. Our sincere thanks go out to all those who have listened, tried to understand and did not tell us we were the lucky ones. Time does heal."

Clinicians working with individuals with brain injury and their families are constantly faced with some or all of these concerns and questions every day. This is the milieu in which the research project was developed.

Evolution of the research idea (The researcher's position)

The interest of the researcher in issues relating to vocational rehabilitation for people with disability began in 1993. This was following his involvement in a community oriented vocational programme providing self employment for people with severe physical disability in the Rehabilitation department of Christian Medical College, Vellore, India (CMC).

CMC's Rehabilitation department was started by Dr. Mary Verghese, who herself had paraplegia (Wilson 1963). In India, people with disability are often responsible for their own medical care and rehabilitation. So the department had to develop an appropriate philosophy for its work. It was decided to adopt the motto of CMC as its own guiding principle – 'Not to be ministered unto, but to minister'. Thus, the department has adopted the principle of helping disabled people to look outwards positively and consider it their right to minister to others, to give to family and society. Central to this philosophy, is the ability and right to work. This philosophy attracted the researcher to vocational issues in people with disability and the project which was called 'Vocational Rehabilitation for the Severely Disabled' (VRSD).

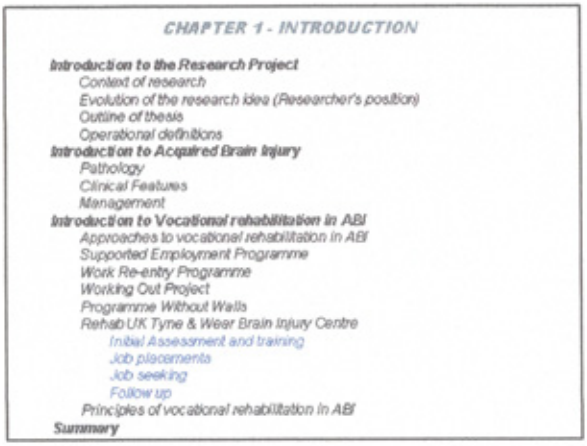
In the course of evaluating previous vocational rehabilitation programmes, the rehabilitation team felt that people with disability needed more support in their return to work. So, VRSD staff not only assessed the person with disability but also assessed the market economy of his local community and matched these to his vocational preferences. A six month residential vocational training, which included personality development and business-sense, was provided. In the fifth month, the place of self-employment and tools required were prepared. After returning home, clients are followed up regularly and counselled. As part of the support to their employment, some were offered top-up training to their skills or re-training if necessary. The initial results published as a descriptive study of 23 clients reported employment rates of 83% at 16 months, 85% at 9 months and 100% at two months (Gurunagarajan, Robinson *et al.* 1995). Subsequent unpublished follow up results were very encouraging and the ongoing success of this project, which is now a full programme rather than a research project, emphasised the need for supported employment.

The researcher then became involved in the process of setting up brain injury rehabilitation services in CMC and came on study leave to the Regional Neurological Rehabilitation Centre, Newcastle upon Tyne. It was here that he came across Rehab UK's Tyne and Wear Brain Injury Centre (Rehab UK). Rehab UK is a registered charity providing vocational training services to adults with brain injury. It is supported by the departments of Employment, Health and Social Services in the area. It has an excellent track record of helping people with brain injury return to work. It subscribes to the principles of supported employment and is based on the Work Re-entry and Supported Employment programmes. The programme works with around 50 new clients each year accepting four or five intakes annually. Each intake consists of 8-12 clients. Each intake goes through the three modules as outlined in the previous chapter: around 12 weeks of assessment and planning combined with centre based training (module 1) , around 5-7 months of job placements and centre based training (module 2) and then job seeking (module 3) followed by up to five years of follow up in employment. Its staff include Clinical Neuropsychologists, Social workers, Occupational psychologists and Job coaches. It had also started using formal objective assessment tools for neurobehavioural aspects (the Neurobehavioural Functioning Inventory (NFI), the Toronto Quality of Life (QoL) scale and an awareness evaluation. Extensive daily records document all aspects of each individual's pathway through the centre based programme. Follow up documentation is also rigorously followed. In addition to the vocational rehabilitation programme, a Community Integration Scheme had also been started. (Berry and Brownlee 2002).

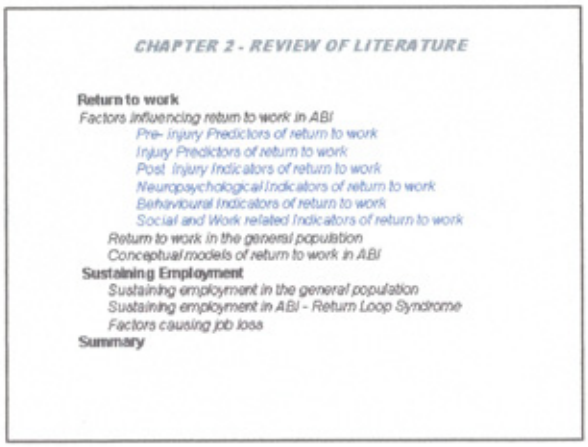
But even though there was an excellent vocational programme for people with brain injury which followed the principles of supported employment, the long term vocational outcomes were still not clear. There was an interest and *clinical need* to explore the issue of long term follow up for individuals with ABI both in Vellore and Newcastle upon Tyne. Clinical issues regarding sustaining employment had not been separated from issues relating to return to work and therefore Rehab UK and CMC's follow up programmes were extensions of the return to work programme rather than a specifically planned programme to maintain and improve job stability. From a research perspective too, the conceptual models of vocational rehabilitation dealt with the process of return to work without including factors involved in the process of long term follow up. Therefore there is no *conceptual model* on which to base long term

clinical follow-up and support to improve sustained employment. There was one study on sustained employment but only the perspectives of the job coach and the programme were researched (Sale, West *et al.* 1991). The important *perspectives from the individual with ABI*, so crucial to the rehabilitation process, as well as the *family and employer,* were mostly not explored (Ownsworth and McKenna 2004). Thus long term follow up with regard to sustaining employment after supported employment in adults with ABI is mostly uncharted territory both from clinical and research perspectives and is an area of research need. Therefore the researcher chose to examine sustaining employment in brain injury as his research project.

Outline of Thesis

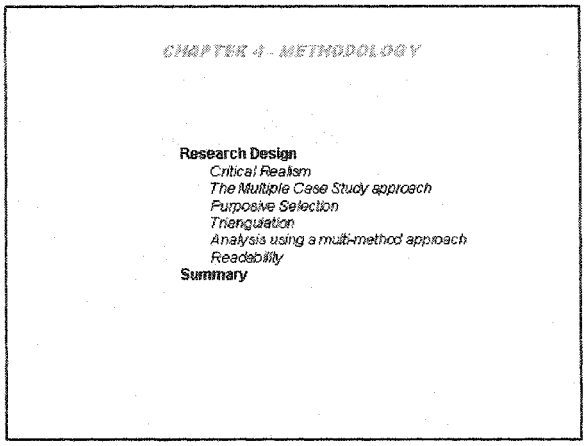


The first part of the research project is presented in this introductory chapter of the thesis. After presenting operational definitions and introducing acquired brain injury, this chapter presents published reviews and reports of supported employment programmes. These were chosen based on available publications or reports. In addition, there were several components of these programmes which have been assimilated in the Rehab UK programme.

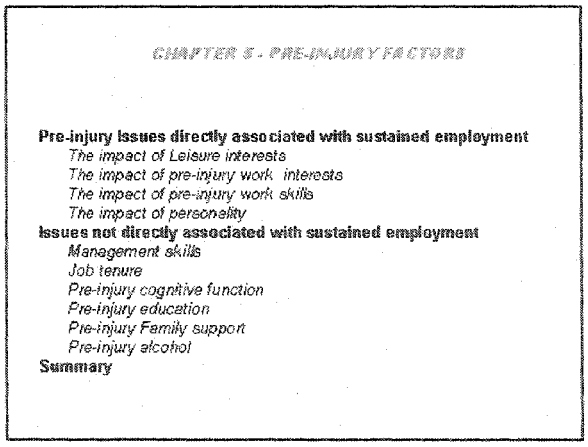


The second chapter in this thesis presents the existing research in this area. Unfortunately, there is very little research done in sustaining employment in brain injury. However research on the closely related topic of return to work is presented as it sheds light on sustaining employment.

The third chapter presents the overall aims and the processes involved in achieving these aims i.e. objectives.

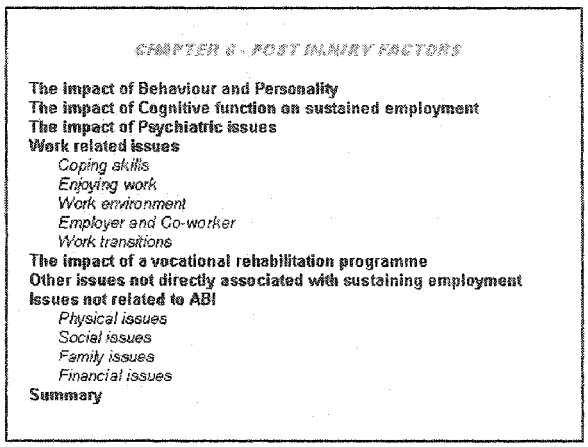


Chapter Four defends the choice of a flexible approach qualitative methodology in researching the subject of sustained employment. It outlines measures taken to improve rigour, trustworthiness and generalizability. It then describes the process of data collection, analysis using software and presentation



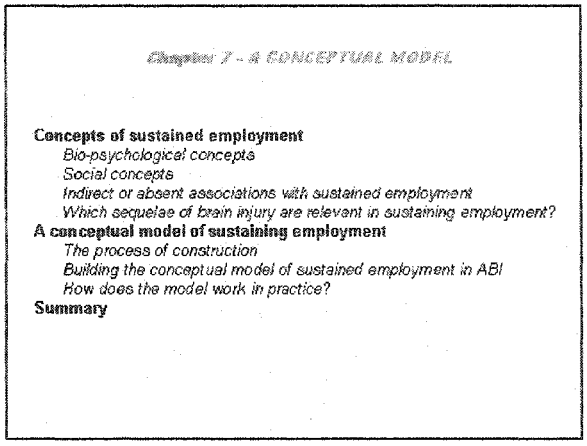
Relevant sections of the textual data are presented in chapters five and six. Each major issue raised by the interviewees are highlighted.

Chapter five highlights pre-injury issues relating to sustaining employment.

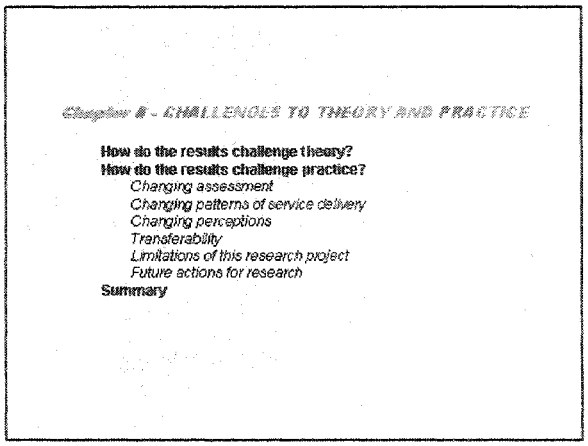


Chapter six highlights post-injury issues relating to sustaining employment.

Some of these issues were reported to be directly associated with sustaining employment i.e. interviewees say that the factor is either positively or negatively linked to sustaining employment and may even describe a process or attribute a reason to this. These issues are mentioned first in both chapters five and six.



After providing direct textual samples for each finding in this piece of research, the development of the conceptual model is described in chapter seven. The process of construction is described and then the issues raised in the previous chapters are conceptualized and a model is constructed. Examples of how such a model would work in real life are outlined to demonstrate the practical usefulness of the conceptual model



The impact of the findings of the research are outlined in chapter eight. The challenges to assessment, service delivery, perceptions and research are described along with issues relating to transferability of the findings of this study. The study is also critically evaluated. Specific proposals which emerge as a result of the interviewees' experience are mentioned in this chapter

In addition to summaries at the end of every section, there is a summary of the whole research in chapter nine which is the concluding chapter.

Appendices provide additional information regarding the preliminary records and documentation followed in the research project. A copy of a publication relating to the review of literature chapter is also placed for reference in the appendices.

Operational definitions

Specific concepts and groups referred to in the thesis are defined in this section to clarify the discussion that follows.

Acquired Brain Injury (ABI) is 'an inclusive category that embraces acute (rapid onset) brain injury of any cause including trauma (head injury or post-surgical damage), vascular accident (stroke or sub-arachnoid haemorrhage), cerebral anoxia, other toxic or metabolic insults (including hypoglycaemia), infections (meningitis, encephalitis) or other inflammations (vasculitis)' (RCP-BSRM 2003).

Vocational rehabilitation refers to 'the overall process if enabling individuals with either temporary or permanent disability to access, return to or remain in employment' (Tyerman and Meehan 2004).

Sustaining employment refers to a multifaceted process which includes not merely the duration of the job (*job tenure* or stability) but also the ability to hold on to a job even when circumstances changed (*job retention*) and progress to better jobs (*career advancement*) (Walker and Kellard 2001). In this study any one of these criteria are taken to define whether sustaining employment was achieved or not.

Supported employment refers to a specialised vocational programme which offers the person with disability long term comprehensive support with the aim of maximizing their residual vocational potential and empowering them.

The case study approach has been defined as 'an empirical inquiry which investigates a contemporary phenomenon especially when the boundaries between the phenomenon and context are not clearly evident and when there are more variables than data points[1] and therefore relies on multiple sources of evidence which need to converge in a triangulating manner and benefits from prior

[1] Data points are units of analysis e.g. a single case study or a set of case studies or a contextual set like all employers from all the case studies.

development of theoretical propositions to guide data collection and analysis' (Yin 2003)

The flexible design in qualitative research is defined as an eclectic approach which emerges and is developed during data collection (Robson 2002).

Triangulation is defines as the process of obtaining more than one perspective to research data (Denzin 1988; Yin 2003).

Coping has been defined as "the constantly changing cognitive and behavioural efforts to manage the internal and external demands of transactions that tax or exceed a person's resources" (Folkman, Lazarus et al. 1986).

Motivation is defined as a general term for 'all the processes involved in starting, directing and maintaining physical and psychological activities'(Zimbardo, McDermott *et al.* 1995).

Association is defined as a relationship between factor and outcome when it is specified in the textual data by an interviewee. In this study, it is neither a statistical nor a mathematical relationship.

A model is defined as an overall framework for looking at reality (Silverman 2001).

A concept is defined as an idea deriving from a model (Silverman 2001).

INTRODUCTION TO ACQUIRED BRAIN INJURY

Acquired brain injury includes all injuries to the brain occurring as a result of a disease process (altered blood and oxygen supply, altered metabolism, infection or inflammation), toxic substances or trauma.

The two commonest cause of ABI are stroke (cerebro-vascular accidents) and trauma. The incidence of under-65 strokes is approximately 20/100000 and that of moderate to severe brain injury is around 25/100000 per year (NICE 2003).

Pathology

The primary injury in strokes and trauma is different. People with stroke tend to have more focal brain injury related to areas of blood supply of the diseased vessel. People with closed traumatic brain injury tend to have more diffuse brain injury or localisation at the polar regions (temporal or frontal) and other areas where the soft brain impacts the hard skull. However this difference in primary injury seems to decrease in significance as the processes of secondary injury take over. These processes of secondary injury are mainly related to changes in pressures – blood pressure to the brain vs. brain tissue pressures. Also, electrolytes and neurochemicals change in response to the primary injury (Rosenthal, Griffith *et al.* 1983). These secondary processes are considered to be more damaging and importantly, they are also potentially treatable. As a result of a common process of secondary damage, though people with stroke and trauma show heterogeneous clinical presentations, from a rehabilitation perspective, they have similar long term residual neurological sequelae and needs (RCP-BSRM 2003)

Clinical Features

Each type of ABI presents with diverse clinical presentations. However, once acute management is completed, national clinical guidelines suggest that they all need to be assessed for common impairments(RCP-BSRM 2003). The common ***physical sequelae*** of ABI are spasticity or tightness of the oro-pharyngeal, facial and limb

muscles. Spasticity commonly affects the whole body (tetraparesis) or one side (hemiparesis). Spasticity interferes with normal voluntary movement of the affected set of muscles. In addition other movement abnormalities like dystonia (abnormal posturing of a part of the body) or ataxia (jerky movements on attempting to perform a movement) may cause similar difficulties. Any of these could affect swallowing and speech. If swallowing saliva is difficult, difficulties with drooling occur. If swallowing food is difficult, malnutrition can occur unless special care is taken to alter consistency of food or provide an alternate route of feeding by a direct tube to the stomach. Poor clarity of speech makes it difficult for the person with ABI to indicate their needs – particularly difficult are indicating bowel and bladder needs which then cause incontinence. Usually gestures and facial expressions can also be affected making alternative forms of communication also difficult. The other less common physical difficulties are sensory difficulties. These are more difficult to diagnose as diagnosis requires communication with the person with ABI. All five senses can be affected. The commonest problem with vision is the loss of a particular field of vision – usually the same half on both sides which causes the person to be blind to things on that side. Sometimes double vision can occur. Loss of hearing, smell and taste may occur less commonly (RCP-BSRM 2003). The sense of touch, rather than disappearing, may become different e.g. touch can feel like pain. Pain sensation can be set off spontaneously without a stimulus (neuropathic pain). Other episodic neurological symptoms may also occur – epilepsy being the commonest of these, though autonomic and sensory symptoms may also occur. But perhaps the most common physical sequelae of ABI is fatigue, the lack of energy comes on within a short time of waking up in the morning and worsens through the day. This may or may not be associated with sleep disturbances and may be relieved by frequent rests or naps.

Cognitive sequelae of ABI are common in ABI. These are not always recognized as sequelae of ABI. Instead, as the person with ABI "looks so normal", he struggles to be accepted socially as his cognitive difficulties do not "not show like a broken leg in plaster (Powell 1994). There are three levels of cognition that are commonly affected in ABI. The *first level* or the basic building blocks of cognition can be affected such as attention, orientation, memory and the ability to learn. It is not uncommon for a person with ABI not to know where he is, or which day or month or year it is. People

with ABI will frequently find themselves distracted by background activity or noise. The ability to recognize patterns - both visual (pictures, shapes, common objects, words or sentences) and auditory (speech) – are less commonly affected. Another less common difficulty is to put patterns of movements together to perform a learned task (Dyspraxia). The next level of cognition that is commonly affected is *executive function.* Executive dysfunction is defined as the ability to put the basic cognitive abilities to use in daily living situations using abilities like planning, prioritization, judging situations and peoples' reactions and deciding appropriate behaviour. The highest level of cognitive ability is also affected in people with ABI i.e. *metacognition.* This is the awareness of cognition. Difficulties at this level will cause a lack of insight, an inability to recognize one's own inadequacies and therefore a lack of motivation (Whyte, Hart *et al.* 1998). In addition to these cognitive difficulties, people with ABI can experience a spectrum of psychiatric conditions and the commonest of these are depression and aggression (Miller, Burnett *et al.* 2003). These can be as a direct result of brain injury to a particular area e.g. the famous nineteenth century example of Phineas Gage who experienced personality changes and bursts of rage after an explosion caused a metal bolt to penetrate his frontal lobe. Though he recovered physically, this industrious railway foreman became an unreliable, homeless drifter (Saper, Iversen *et al.* 2000). These difficulties may also be because of associated depression or post traumatic stress which are a result of the traumatic experience and tragic changes in circumstances through which a person with ABI has to pass. Apart from clinical depression, people with ABI have been known to experience psychotic symptoms such as delusions and hallucinations or even obsessive compulsive personality changes.

With regard to ***socioeconomic sequelae*** of ABI, people with ABI have a greater proportion of behavioural challenges than cognitive and physical needs (Kolitz, Vanderploeg *et al.* 2003). This poses a particularly poignant problem for them as they do not have visible needs and therefore are often misunderstood. Uncontrolled outbursts of rage can occur, causing disruption within the family and it is not uncommon for a person with ABI to be the main cause of his own isolation both from family and society. Tolerance to alcohol decreases after ABI and this further aggravates tensions in social settings. A large proportion of people with traumatic brain injury are young men with pre-injury difficulties with substance abuse or

violence. They often drop out from the Neurorehabilitation programme's follow-up (Corrigan, Harrison-Felix *et al.* 2003). Neurobehavioural sequelae in this group also have an impact on peer interaction. Peer interaction also helps the process of empowerment. But individuals' impaired social skills and judgement impede the spirit of what could otherwise be a powerful tool of advocacy and social change. Cognitive and behavioural issues also compound the problem of social and vocational reintegration which are a particular challenge for people with ABI (Sumners and Lewin 1993).

Finally, the vocational sequelae of ABI are frequently disastrous for the individual. In one sub segment of ABI - traumatic brain injury - a national register in the US showed that only 22% returned to work at 1 year after injury (NIDRR and TBIMS-Database 2000). An assessment for the first year after traumatic brain injury revealed employment decreasing from 69% to 31% and a decrease of 51% in earned monthly income (Johnstone, Mount *et al.* 2003). However, this is not merely a matter of concern for the individual. There is a great economic impact as a result of brain injury. Through traumatic brain injury alone, a recent US estimate showed losses of $642 million in wages, $ 96 million lost in income taxes and $353 million lost through increased public assistance (Johnstone, Mount *et al.* 2003). Thus, return to work in ABI is an issue that is important not only for individuals and service providers, but also to the community at large.

Management

The management of ABI is supportive rather than curative (NICE 2003). While it has been discovered that the human central nervous system has some capacity to regenerate (Horner and Gage 2000), there are no direct treatments as yet that can reverse brain injury. Based on evidence, national guidelines have been formulated both for acute management and transition to rehabilitation services (NICE 2003). The process of recovery in an individual with ABI is gradual and full recovery is a rarity. Maximal gains can be expected in the first year after injury (Rosenthal, Griffith *et al.* 1983). The main thrust in ABI, therefore, is rehabilitation - especially for cognitive and behavioural difficulties and the use of compensatory approaches (Miller, Burnett

et al. 2003). Often a patient-centred approach will need to be combined with support for the patient's family or carers, whose perceptions may not always concur (Hart, Whyte *et al.* 2003). A goal directed rehabilitation approach should be offered as soon as possible.

In the acute stages of intensive care, national clinical guidelines suggest reducing impairment or pathology. Interventions would focus on prevention of contractures, pressure sores, deep vein thrombosis and complications of tracheostomy, nasogastric or percutaneous endoscopic gastrostomy feeding tubes and catheters. Appropriate nutrition is also considered (RCP-BSRM 2003).

In the post acute stages, the goal becomes reducing disability or improving activity. Interventions would focus on maximizing motor, behavioural and cognitive function to enable mobilize the person and make him independent in activities of daily living..

In the community, the goals of rehabilitation focus on extended activities of daily living and social, vocational or educational re-integration (RCP-BSRM 2003). Advocacy within local communities and government should be carefully coordinated effort between people with ABI, their family and carers and their rehabilitation service providers. All this makes the area of rehabilitation of those with ABI a particularly challenging task. There is a mismatch between the number of people with ABI and the availability of appropriate specialist Neurorehabilitation services. Thus appropriate Neurorehabilitation services are often not always available to people with ABI (Powell 1994; Tyerman and Meehan 2004).

VOCATIONAL REHABILITATION FOR ABI

The word '**Vocation'** is often used to specify a profession or trade. But vocation also means choice of a life's career and a predisposition to a particular calling. Vocational rehabilitation is therefore more than just getting a person back to work. It is integrally woven into an attempt to bring back choices into a person's life. It is often the person's way back to his or her calling and life work. It is a route for a person with disability to gain back his right to give to society (Macaden 2005).

Vocational rehabilitation is defined as the attempt to maximize vocational potential and function. Vocational rehabilitation addresses vocational needs at the three levels of impairment, activity and participation (WHO 2001; Macaden 2005).

Approaches to vocational rehabilitation in ABI

Attempts to help people with ABI return to work are fairly recent. In the past, individuals with ABI were not given an opportunity to demonstrate their competency in work situations because traditional vocational rehabilitation approaches in ABI only offered pre-placement evaluations and gave advice based on these evaluations. Both evaluation and advice were based in the training centre and their effects were expected to be transferred or generalized to real life situations at work. Work hardening (a process of improving a person's endurance in the work situation) was offered as a method of improving physical ability to work (Wehman, West *et al.* 1995). Some older services offered simulated work situations in adult day centres, sheltered workshops or segregated institutions (Fraser, Cook *et al.* 1997).

The actual process of return to work was carried out through a counsellor or counselling services locally. These local services exist even today, but the results are not good. State-run vocational services for the disabled in the US return around only 24% of people with ABI to work (O'Neill, Zuger *et al.* 2004). However, even if these services were provided by brain injury rehabilitation programmes, the results were not encouraging. In 1987, a 2 year follow up of 4 brain injury rehabilitation programmes was reported as having less than 3% maintained competitive employment (Ben-Yishay, Silver *et al.* 1987). Return to work was less than 40% in a day care

programme (Haffey and Abrams 1991) and averaged in the range of 20 - 30% (Ip, Dornan *et al.* 1995; Greenspan, Wrigley *et al.* 1996; Sander, Kreutzer *et al.* 1996; Cattelani, Tanzi *et al.* 2002; Tyerman and Meehan 2004).

There were two major drawbacks to these vocational rehabilitation programmes.

1. They were "horizontal" programmes - common for all people with disability. Under 3% of the caseload of a US district disability vocational services counsellor would be people with traumatic brain injury, even though they are above 6-8% in the community (O'Neill, Zuger *et al.* 2004). This meant that the special needs of people with ABI could not be specifically addressed with specialized approaches. This is particularly relevant for their cognitive and behavioural needs.
2. The transfer of work related skills from rehabilitation centre to real life work place did not occur spontaneously (Wehman, West *et al.* 1995; Johnstone, Mount *et al.* 2003).

This was recognized by several service providers and so "vertical" programmes have evolved with emphasis on specific evaluation and intensive support for transference of work related skills to the work place. These programmes are fairly recent, having begun in the eighties. Most of these programmes were designed for individuals of working age with severe traumatic Brain Injury (TBI) who could not work without ongoing job support. Generally individuals with substance abuse were excluded. (Wehman, Kreutzer *et al.* 1990; Tyerman 1999; O'Neill, Zuger *et al.* 2004) . There were very few published reports of these modern programmes and a few unpublished reports to appropriate government departments. Programmes for whom information was available in the public domain have been presented below.

Supported Employment Programme

The Supported Employment (SE) programme was the earliest to publish case studies from researchers in the Medical College of Virginia (Wehman, Kreutzer *et al.* 1988). This programme is defined as competitive employment in an integrated setting with

on going supports for individuals with TBI (Wehman, West *et al.* 1995). It was different from other approaches in two aspects:

- Individual placements were made into competitive positions paying at least minimum wage
- On site training and support services were provided by a trained rehabilitation professional who was called a Job Coach or Employment Specialist.

There were three stages in the SE programme. The first stage provided an extensive initial assessment which included medical and neuropsychological examinations, analysis of work environments as well as assessment of the person's abilities and interests.

The next step was for the Job Coach to place the individual and provide job site training based on the findings of the assessment stage. This second stage was seen as an interactive process and feedback from all parties was obtained. The Job Coach would then use the feedback to re-structure the environment or address particular concerns. This stage usually lasted around 16 weeks and actively occupied the Job Coach for slightly less than 300 hours.

The last stage was for the Job Coach to continue to support the individual's performance and then gradually fade out of the employment process.

Researchers were encouraged by an outstanding result of 70% of SE attendees returning to work (Wehman, Kreutzer *et al.* 1990).

Evaluating the efficacy of supported employment programmes with a randomised double blind control trial has not been possible, primarily because of the ethical difficulties of withholding vocational services to a control group especially when it is known that reports as low as a 2% return to work have been reported in the absence of vocational rehabilitation (Ben-Yishay, Silver *et al.* 1987). However, the viability of SE programmes has been supported by cost-benefit analysis studies which were returned to their government funding agencies. This was done using comparison rather than control groups on 4000 clients in one state in the US, comparing

longitudinal incomes and service costs with encouraging results. The economic viability of the SE approach is being similarly demonstrated with qualitative and economic variables in small groups (Ponsford 1995; Dean, Dolan *et al.* 2003). One recent 14-year longitudinal study reporting individual earnings of $17,515 more than costs associated with their SE (Wehman, Kregel *et al.* 2003).

The cost effectiveness of SE programmes is accepted by governmental agencies. It is estimated that in the US, the number of clients in supported employment programmes had increased from around 10000 in 1986 to around 139000 in 1995 (Wehman, Kregel *et al.* 2003). Also, the 1986 Rehabilitation Act ensured funding for SE and over 150000 people have returned to work as a result. Many successful vocational rehabilitation services work on the principles of the SE approach (Wehman, Kreutzer *et al.* 1990; Gurunagarajan, Robinson *et al.* 1995; Ponsford 1995; Sander, Kreutzer *et al.* 1996; Tyerman 1999; Berry and Brownlee 2002; Tyerman and Meehan 2004).

Work Re-entry Programme

The Work Re-entry programme was developed by the Sharp Rehabilitation centre, San Diego and was characterised by a preference to return people with TBI to their previous employment.

The assessment was limited to vocational assessments and they reported that situational assessments and simulated work samples proved to be most useful. Conventional assessments did not correlate with outcome. Work hardening was used as a preparatory intervention.

Vocational counsellors carried out job development, analysis and placement. This involves around 41 to 60 hours of assistance.

Also, the person with TBI could also be placed in a Transitional Employment Programme in which Job Coaches were used to help these individuals with competitively paid placements in the rehabilitation centre's kitchen and maintenance departments. This involved around 85 hours of assistance.

The Work re-entry programme concluded that ongoing specialized and individualized support and preparatory day care were useful as were a strong pre-injury work history, good family support and a sense of responsibility for the injury. These were more relevant to employment outcome than length of coma or Rancho Los Amigos Cognitive function levels. The Work Re-entry programme concurred with the SE programme about the need to support the individual's reduced capacity to adapt to changes at work as a result of the ABI.

The major difference from the SE Programme was that follow up was limited to the first 60 days and then to phone calls every 6 months. They agreed that there was a need for continued support and admitted that it was resource constraints rather than philosophical differences, that limited ongoing support beyond the first month. However, they pointed out that despite the limited follow up period, their return to work rates (68%) and job retention rates (71%) were comparable to the SE programme and far superior to the return to work rate of the day treatment group (34%), but they were able to service 130 clients in three years compared to 53 clients in the SE programme. However, they refrained from advocating the work re-entry programme as being better than the SE programme as long term follow up data on sustaining employment was not available (Haffey and Abrams 1991). In fact in their report to their Social Security administration, they admit that the lack of long term follow up is a major concern and that they obtained a new grant to enhance long term follow up for three further years (Abrams, Barker *et al.* 1991) which is as yet unpublished.

Working Out Project

The Working Out Project is a specialist vocational rehabilitation programme and was developed for individuals with TBI by the Community Head Injury Service, Aylesbury Vale Community Healthcare NHS Trust. It was funded by the Department of Health between 1992 and 1997 and it continues to offer these services.

The assessment phase included vocational interviews, specialist neuropsychological and occupational therapy assessments. They reported that the Functional Assessment Inventory and the Work Personality Profile were the most helpful in discriminating

those who would return to paid employment, while conventional assessments did not correlate with outcome.

Then group activities (personal issues groups, work preparation groups or core groups) and individualized work counselling were used to prepare individuals for voluntary work trials or placements. This approach differed from others in that intake was part of a community head injury programme and assessments and follow up were on a broader base than a purely vocational goal. The team, rather than a particular individual, continued to provide follow up.

The Working Out Project reported a 67% return to paid employment. However if therapeutic earning and voluntary work were included, it reported that 85% of its intake were positively placed. In a report to the Department of Health and Employment Services, it reported that if savings in benefits and tax revenues as a result of return to work were calculated, the pay back period to cover costs of such a programme was 21.6 months. They reported that in their project, net savings to the exchequer were accumulating over three years at a rate of £300 per month (Tyerman 1999; Tyerman and Meehan 2004).

Programme Without Walls

Programme Without Walls was developed for individuals with TBI by the Department of Educational Foundation and Counselling Programs at the Hunter College, New York. Intriguingly, Programme Without Walls does not refer to the SE programme, but includes job coaching and long term follow up as a key part of its practice. This programme, like the SE programme, emphasises an individualized strong relationship with a counsellor through person centred planning. A new and different emphasis in Programme Without Walls is the provision of assessment and support services based in the community rather than at the vocational rehabilitation centre. It does this through a team of 'freelance consultants' who are paid on an hourly basis. This team is accountable to the state vocational rehabilitation programme counsellors. The assessment phase of Programme Without Walls is primarily neuropsychological. When vocational assessment is done, this is done in the community. As in the SE

programme, the community based team help in job placement and continue to be available to the individual after return to work.

Programme Without Walls reported that 57% of their clientele successfully returned to work compared to 24% of those who accessed the general vocational rehabilitation service through counsellors alone. Though this is not as successful as the SE Programme or the Work Re-entry Programme, the concept of a hired community 'Job Coach Team' is reported as a good model for communities with few specialized resources for brain injury (O'Neill, Zuger *et al.* 2004).

Rehab UK Tyne and Wear Brain Injury Centre's Vocational Rehabilitation Programme for ABI

Vocational rehabilitation services for ABI were set up around Newcastle upon Tyne by the Rehab UK Tyne & Wear Brain Injury Centre as a synthesis of best published practice (Berry and Brownlee 2002). An intake of around 20 clients was selected every six months and they were offered vocational rehabilitation in three phases:

Module 1: Initial Assessment and training

The first phase was the assessment and planning which focussed on individual work based skills and environmental opportunities and responses.

The neuropsychological, medical and social **abilities** of the client were perceived from this viewpoint. The individual's abilities in areas of functional independence, mobility, transfers, transportation, cognition, executive function, behaviour, stress management and safety were observed. Neurobehavioural aspects were of special importance as motivation, behaviour and interpersonal relationships play an important role in sustaining employment. While test batteries and specialist scales are useful, none could comprehensively discover all the abilities or identify all the vocational potential of a client (Tyerman 1999). So their abilities were also observed and analysed using 'SWOT' (strength, weakness, opportunities, threats) analysis (Brooke, Inge *et al.* 2003).

The individual's **felt needs** were identified. The individual's *felt needs* refer specifically to a subjective feeling usually of a basic need. This is considered to be different from their *expressed need* which is an expressed subjective feeling, their *normative needs* which are those defined by experts based on the socially accepted norm and their *comparative needs* which are those based on met needs of others like them (Bradshaw 1981).

Once their felt needs and abilities were identified and analysed, they were matched to each other and the individual and the Rehab UK key-worker sat down together and agreed on goals and time frames for the vocational rehabilitation programme. Progress along this **goal directed pathway** was followed up and modified depending on the evolving situation.

Once the individual's abilities and work based skills were known, **environmental opportunities** were assessed. This included assessing skills required for the job development processes e.g. preparing a resume', business interview skills and phone conversations including simulated calls to employers (Vandiver, Johnson *et al.* 2003). Potential employers with whom the individual could undertake a placement are identified. The Job Coach's pre-existing organizational marketing infrastructure and community networks came into play here and they marketed the individual and his skills to employers within their network.

Module 1 usually lasted for around 12 weeks.

Module 2: Job placements

The next module was simulated employment. The Job Coach played a central role from this point. Appropriate placement options had been selected in the initial stage in the light of the assessments and observations (Vandiver, Johnson *et al.* 2003). During a job placement, assessment and feedback continue with job duty analysis by the individual, job coach and the employer. It was often the case that employers actually benefit from the experience as they had work done in an environment of evaluation and support and had the opportunity to continue or stop the experience at the end of six weeks without any financial or legal implications.

The process of placements continued until a satisfactory result was obtained. There is no time limit for module 2 as it is continued till the person is ready for employment with placements going on alongside centre based activities. A sample weekly schedule for the first 2 modules is shown in Table 1.1 (Berry and Brownlee 2002).

Table 1.1: Rehab UK Vocational Programme's Initial stage modules

Timetable for modules 1 and 2							
	Module	**10.00 to 10.30**	**10.30 to 11.15**	**11.30 to 12.15**	**13.00 to 13.45**	**14.00 to 14.45**	**15.00 to 15.45**
Monday	1	Client directed morning meeting	Information technology	Information technology	Project resource time	Project resource time	Project resource time
	2		Vocational guidance	Self directed Vocational guidance	Computer time	Core skills	Information technology
Tuesday	1	Job seeking skills	Job seeking skills	Feedback session	Work related social skills	Work related social skills	Cognitive training
	2	Self directed job seeking	Self directed job seeking	Feedback session	Vocational guidance	Self directed Vocational guidance	Communication skills
Wed	1	Client directed morning meeting	Work related social skills	Work related social skills	Information technology	Cognitive training	Cognitive training
	2		Cognitive training	Cognitive training	Vocational guidance	Information technology	Information technology
Thurs	1	Client directed morning meeting	Personal development	Cognitive training	Cognitive training	Core skills	Information technology
	2		Core skills	Information technology	Vocational guidance	Volunteer Placement Planning	Cognitive training
Friday	1	Client directed morning meeting	Information technology	Core skills	Weekly review	Group Key worker session	
	2		Action IPP goals	Vocational guidance	Weekly review Project work	Group Key worker session	

Module 3: Job seeking

The final phase in a supported employment programme is job seeking. In this module, job seeking activity is supported both at and outside the centre. Within the centre, simulated interviews, preparation of CVs, job applications are continued. Again, there is no time limit to this module.

Follow up

Once the client returns to work, the issue of sustaining employment long term is addressed by the Job Coach who continues support and provides re-training when necessary. Rehab UK usually offers support for five years though it could be a life long process.

The Job Coach supported the process of return to work using internal and external supports.

Internal supports are processes that the person with disability trains himself to use or which address the individual needs of the person. These would include those needs traditionally considered in a medical model. Internal supports would be provided by evaluation and intervention provided by rehabilitation nurses, medical doctors, physical, occupational and speech therapists and psychologists. Multidisciplinary rehabilitation teams largely provide internal supports. ***External supports*** are processes instituted in or on the surrounding environment. These would be considered within the scope of the traditional social model and would include evaluation and intervention provided by social workers or care managers, community therapists and nurses, teachers, employers and care workers. Community teams and vocational programmes largely provide external supports.

Both internal and external supports need to be provided in a coordinated manner to enable the person with ABI to return to work. As described in preceding sections, these supports were traditionally provided in a serial manner – internal supports first followed by external supports with some overlap.

Common internal and external supports are outlined in Table 1.2 (Brooke, Inge *et al.* 2003).

Table 1.2: Internal and external supports in SE

Support for:	Internal supports	External supports
Changing systems and their power to support	Physical enablement. Cognitive enablement e.g. initiation, dyspraxia, insight. Behavioural enablement e.g. coping skills for anger, stubbornness, consistency	Education. Control substance abuse.
Importance of Relationships & Importance of Community	Develop self image. Develop motivation. Education on rights, privileges and opportunities.	Financial aid. Modify level of responsibilities. Adapt job environment.
Capacity and Capabilities.		Specific vocational training. Compensation. Assistive technology. Networking.
Ensuring employment, Competitive employment, With commensurate wages & benefits controlled by individual.	Positive family support – interdependent rather than dependent or undependable.	Social support. Peer support. Employer support. Co-worker (twinning) support.

The Job Coach also needed to develop natural external supports in the work place by training a co-worker to be a mentor (Fraser, Cook *et al.* 1997). The mentor might need to help with cues in the workplace (a cue being a feature which would indicate to the individual what to do next). If cues were insufficient, verbal or gestural prompts were introduced. Once successfully instituted, cues or prompts were gradually weaned off. Other compensatory aids like imagery, mnemonics, a reminder notebook or whiteboard and rehearsals were also used. The use of Assistive Technology and environmental engineering (ergonomic placement of commonly used articles, colour coded documents, cue cards at appropriate places), prosthetic memory aids (tele-memo watches, diaries, phones with number memories, Dictaphones) and cognitive orthotic devices (spell check or word finding software) were considered in this phase. (Parenté, Stapleton *et al.* 1991).

The roles of a job coach are outlined in Table 1.3 (Brooke, Inge *et al.* 2003) .

Table 1.3: Roles of a job coach (Brooke, Inge et al. 2003)

Job coach Roles	What it entails
Planner Role	Assess the client (customer profiling), assessing various job sites to match them with the client (resource matching) and training the client for interviews (résumés, cards, handling phones) using the person centred planning approach.
Consultant Role	Provide recommendations to the client to get and keep a job.
Head Hunter Role	Organizational marketing (building and maintaining a network of job providers) market and employer surveys and matching using a market based planning approach.
Technician Role	Provide rehabilitation solutions for problems with transfers, cognitive dysfunction and other disabilities at the work site. Suggest assistive technologies and develop natural supports at the work site.
Community Resource Role	Networking and creative linking. Equally fading from the job site neither too slowly (creates dependence) nor too fast (results in job losses).

The Job Coach is alternatively called trainer advocate, job trainer, supported employment training specialist or Employment specialist (Brooke, Inge *et al.* 2003). It is desirable for a Job Coach to have skills in psychology, counselling, education, marketing and business as well as an understanding of medical, therapy and nursing issues facing the person with ABI. Thus the role of the Job Coach is perhaps too broad to be realistically performed by one person. As can be imagined, the fulfilment of all these roles by one person would be quite difficult. However, "*it is amazing what can be accomplished when nobody cares about who gets the credit" (Yates 1738-1801).* A major difference from the other programmes is that the Job Coach in Rehab UK's programme is supplemented by an occupational psychologist, a clinical psychologist and a social worker. The team rather than the individual actually fulfil these tasks (Berry and Brownlee 2002).

Thus, the above mentioned vocational rehabilitation programmes for ABI have common principles and minor differences.

Principles of Vocational Rehabilitation

The key principles of rehabilitation are to maximize residual potential, to be comprehensive in approach and to empower individuals with disability and their families (Delisa, Currie *et al.* 1998). Do vocational rehabilitation programmes fulfil these general principles?

Maximize residual potential

It is apparent that all successful vocational approaches agree in principle to support employment by:

- a **specialised vocational programme for** brain injury
- a **Job Coach or similar support team**
- **long term support** and follow up.

As described in preceding sections, these three common principles enable individuals with ABI to maximize residual employment potential. These principles of supporting employment have been adopted by Rehab UK's vocational programme and ***the term 'Supported Employment' (SE) used henceforth refers to this generic approach of vocational rehabilitation rather than the Medical College of Virginia's Supported Employment Programme*** described in the previous section.

Be comprehensive

Most vocational rehabilitation programmes, in an attempt to be comprehensive philosophically, put together the medical and social models in a serial manner – assessments under a medical model system and counselling, placement and follow up under a social model set up. The medical model of vocational rehabilitation focuses on addressing the difficulties in the person with disability while the social model would focus on addressing the social aspects creating difficulties for the person with disability. The SE Programme proposes a closer synthesis of medical and social models with the role of synthesis being assigned to the Job Coach. When both medical and social models work together this has been called the partnership model (Barnes and Ward 2000) or the Biopsychosocial model (WHO 2001). This eclectic Partnership

or Biopsychosocial model would address the individual needs of the person with ABI in relation to work and brain injury, and also their needs at the work place and with the employer. Thus vocational rehabilitation must philosophically work on a combined medical-social model of rehabilitation.

Empowerment

To empower people with ABI, vocational rehabilitation is designed to be customer driven. This means that the power and control of decisions are handed over to the person with disability. This is especially important in vocational rehabilitation as empowerment can positively influence motivation. When choosing a life's career or deciding on a calling, the long term results are always better when the individual has the freedom to choose from the options that the vocational rehabilitation programme lays before him (NICE 2003).

While most programmes try and accomplish this by improving accountability of the staff to the individual with ABI, the SE Programme actually proposes a bill of rights described in Table 1.4. (Brooke, Inge *et al.* 2003).

Table 1.4: Bill of rights for a person with ABI in a vocational rehabilitation programme

Every person with ABI is entitled to claim...	
Presumption of Employment	A conviction that everyone, regardless of the level or the type of disability, has the capability and right to a job.
Competitive Employment	A conviction that employment occurs within the local labour market in regular community businesses.
Control	A conviction that when people with disabilities choose and regulate their own employment supports and services, career satisfaction will result.
Commensurate Wages & Benefits	A conviction that people with disabilities should earn wages and benefits equal to that of co-workers performing the same or similar jobs.
Focus on Capacity & Capabilities	A conviction that people with disabilities should be viewed in terms of their abilities, strengths, and interests rather than their disabilities.
Importance of Relationships	A conviction that community relationships both at, and away from, work lead to mutual respect and acceptance.
Power of Supports	A conviction that people with disabilities need to determine their personal goals and receive assistance in assembling the supports necessary to achieve their ambitions.
Systems Change	A conviction that traditional systems must be changed to ensure customer control.
Importance of Community	A conviction that people need to be connected to the formal and informal networks of a community for acceptance, growth, and development.

Thus vocational rehabilitation programmes maximize residual employment potential by using specialized strategies and Job coaches to support employment in the long term. They are comprehensive in their approach by including both medical and social model approaches within their programmes and help to empower individuals with ABI by offering a customer driven approach.

SUMMARY

Many individuals with ABI have a greater proportion of cognitive and behavioural difficulties than physical challenges.

In the past, their social and vocational reintegration into society has been poor.

Vocational rehabilitation programmes have increased the number of people with ABI returning to work in a cost effective way by using principles of supported employment:
They provide a separate, specialised vocational programme for ABI.
They use Job Coaches or equivalent teams.
They provide work placements and long term support for employment.

CHAPTER 2

REVIEW OF LITERATURE

Results! Why, man, I have gotten a lot of results. I know several thousand things that won't work.

Thomas A. Edison (1847 - 1931)

The process of return to work has been studied to some extent both in the general population as well as in individuals with ABI. Though various factors and Conceptual models of return to work have been proposed, a clear picture of this process is yet to emerge. Research into sustaining employment after returning to work is sparse. Thus, after standard searches through Medline, links and bibliography of existing papers were explored. Department of Health reports were searched and a trail was also obtained from their references. Personal contact with practitioners and researcher's in the field in the UK, US and India were also sought and some references and unpublished reports were obtained in this manner. A summary of this literature review is presented in this chapter.

RETURN TO WORK

The challenge of returning adults with ABI to work has occupied the energies of vocational rehabilitation programmes and researchers for at least two decades. Most of the research is from the viewpoint of the service provider. Conceptual models of return to work in ABI have been suggested. Also, there are several 'return-to-work' issues in common with the adults with ABI and the general population. However there is ***no*** description of the viewpoint of the individual with ABI regarding the process of return to work and there is very little information from employers and families.

Factors influencing return to work in ABI

There are very few studies which look at which variables are consistently related to employment outcomes. There have been two attempts to provide a systematic review of the factors influencing return to work and these are described first (Crepeau and Scherzer 1993; Ownsworth and McKenna 2004).

Crepeau and Scherzer published a meta-analysis in which they searched for articles relation to predictors and indicators of return to work in individuals with severe traumatic brain injury published between 1967 and 1990. Studies on return to education and non competitive employment were excluded. Only 41 out of 140 potential studies were deemed suitable for meta-analysis. Each paper was classified based on its homogeneity to other similar papers and the statistical significance of its findings. Thus three types of papers emerged in the meta-analytical hierarchy: papers with significant findings and good homogeneity, heterogeneous papers with significant findings and very homogeneous papers without significant findings. Being above 60 years old was reported to be strongly related to worse work status. The following factors were reported to be moderately related to worse work status: having Frontal and other CT brain abnormalities, language, attention and visuospatial deficits, associated injuries, depression, poor ambulation, overdependence, a long hospitalization and lack of vocational rehabilitation services. Specific findings of physical, cognitive and behavioural assessments were also moderately related to work status. However, a majority of the other factors (family support, litigation, irritability,

executive function, memory, slowness, intolerance to light, noise or bustle, fatigue, loss of initiative and awareness of deficits, driving status, epilepsy, neurological assessments, neurosurgical interventions, hydrocephalus, education, pre-trauma work status, type of injury, demographic variables) were only weakly associated or not associated with work status. These findings are summarised in Table 2.4 (Crepeau and Scherzer 1993).

Ownsworth and McKenna examined around 85 papers published between 1980 and 2003 have addressed the question of which factors in ABI are associated with good employment outcome. The basic message was that most of the factors examined could not be definitively associated with return to work. But this is not for the lack of research. It is primarily because there is high variability among a relatively small number of individuals. Outcomes in vocational rehabilitation are not easily quantifiable and there are no standardized ways of measuring outcomes or delivering interventions and no conceptual understanding of the process as seen by the person with ABI i.e. no gold standards to compare against (Ownsworth and McKenna 2004). Because of these drawbacks, previous research serves as a guide, mostly to describe what doesn't work or, more worryingly, to propose conflicting reports of what does work. This critical review was done by these two raters with a high level of agreement between them (Kappa = 0.835, $p<0.001$). They chose papers studying the effect of different variables on competitive employment among individuals with ABI. They excluded papers if aetiology was unspecified or mixed. Papers relating to social or functional outcomes other than competitive employment were excluded. They rated the methodology of these 85 studies on a nine point scale and eliminated studies with flawed methodology (35) from the review. The remaining 50 studies were classified into marginal (31), acceptable (14) and commendable (5) studies. Using an alpha level of 0.05 and giving less consideration to marginal studies, percentages of studies significantly associating each variable with employment outcome were tabulated. Tables 2.1 to 2.5 are reproduced from this critical review. The percentages refer to the percentage of studies significantly associating the variable with employment outcome. The numbers in brackets denote the total number of studies in each subgroup which actually examined the variable concerned i.e. denominator of the percentage e.g. 100% (5) for papers rated commendable for 'functional status at discharge' means all 5 commendable studies looked at this variable and found a significant association

with employment outcome. 0% (2) for papers rated acceptable for race means that 2 out of the 14 acceptable papers looked at race and employment outcome but neither of them found a significant correlation. This notation is followed through Tables 2.1 to 2.6 and thus a good idea of the inconsistencies of available data is obtained by perusing this data. A summarising comment is also tabulated (Ownsworth and McKenna 2004).

Pre injury predictors of return to work in ABI

Predictors are described as factors which can be used to predict employment outcome. These predictors may not be related to ABI as they are variables present before the injury (*pre-injury predictors*) e.g. age, education, work history, substance abuse and marital status. Despite being poorly associated with predicting outcome, *predictors affect the process of return to work* e.g. Positively, older age has been associated with increased work experience. Negatively, older age is associated with less flexibility in returning to a different or lower level of work. Most pre-injury predictors apart from these (race, education, gender, marital and socioeconomic status and personality) were found to have conflicting results in different studies and a full list of pre-injury predictors and their association with employment outcome are seen in Table 2.1 (Ownsworth and McKenna 2004).

Pre-injury Predictors

- Severely injured below age of 4 – no one was able to work in adulthood
- Injured at 17-25 got jobs better than those who had ABI before 17
- Injured before 40 got jobs better than those who had ABI after 40
- Those without substance abuse 8 times more likely to be employed than those with pre-injury substance abuse.

Table 2.1: Critical review of Pre-injury Predictors associated with employment outcome (Ownsworth and McKenna 2004)

Pre-injury predictors	% = Percentage of studies significantly associating predictor with employment outcome. (n) = no. of studies which examined the predictor			
	Papers rated Marginal n=31	Papers rated Acceptable n=14	Papers rated Commendable n=5	Level of empirical support
Age (time of injury)	54% (11)	40% (5)	50% (4)	Mixed findings
Age (time of study)	30% (10)	67% (3)	0% (1)	Mixed findings
Gender	9% (11)	0% (5)	0% (3)	Low support
Education	20% (15)	60% (5)	60% (5)	Mixed findings
Marital Status	20% (5)	50% (2)	67% (3)	Mixed findings
Race	0% (4)	0% (2)	67% (3)	Mixed findings
Socio-economic status	50% (2)	-	-	Mixed findings and insufficient research
Pre-injury occupational status	43% (14)	86% (7)	50% (2)	Moderate support
Pre-morbid psychological status	0% (2)	50% (2)	-	Low support and insufficient research
Prior concussion or neurological event	0% (1)	33% (3)	-	Low support and insufficient research
Pre-morbid substance use	40% (5)	50% (2)	-	Mixed findings

Injury predictors of return to work in ABI

There are predictors of employment outcome which are related to the actual ABI (*injury predictors*) e.g. (see box opposite) post traumatic amnesia (PTA), time since injury, length of hospital stay, extent of brain damage, level of function at discharge (Cifu, Keyser-Marcus *et al.* 1997). But the same research also reports that the Functional

Injury Predictors

- Highest rate of return to work is 1-6 months after injury and early return is associated with better outcome than those who took longer than 2 years to return to work.
- A considerable number of people who never lost consciousness were unable to return to work.
- Closed head injuries had better outcome than penetrating ones, and if penetrating, >7mm widening of third ventricle predicts outcome best.
- Better function at discharge is a good predictor of employment outcome

Independence measure (FIM) at discharge is poorly related to outcome. From a critical review of papers seen in Table 2.2, it is apparent that with the exception of functional status at discharge, there is very little indication that predictors can consistently predict outcome.

Table 2.2: Critical review of Injury Predictors associated with employment outcome (Ownsworth and McKenna 2004)

Injury predictors	% = Percentage of studies significantly associating predictor with employment outcome. (n) = no. of studies which examined the predictor			
	Papers rated Marginal n=31	Papers rated Acceptable n=14	Papers rated Commendable n=5	Level of empirical support
Time since injury	11% (9)	-	0% (1)	Low support
Length of coma	64% (11)	50% (2)	100% (1)	Mixed findings
PTA	57% (7)	100% (2)	50% (2)	Mixed findings
Glasgow Coma Scale	43% (7)	50% (6)	33% (3)	Mixed findings
CT scan results	50% (2)	67% (3)	-	Mixed findings
Cause of injury	50% (2)	67% (3)	0% (4)	Mixed findings
Length of stay	40% (5)	67% (3)	50% (2)	Mixed findings
Functional status at discharge	63% (8)	86% (7)	100% (5)	Strong support

However despite not revealing associations between variables and outcome, a study of the process by which injury predictors affect outcome is informative e.g. the type of injury: Non accidental brain injury is often accompanied by a sense of responsibility which helps return to work as against traumatic brain injury which is often accompanied by a sense of victimization which adversely affects return to work (Greenspan, Wrigley *et al.* 1996; Tyerman 1999; Sherer, Nick *et al.* 2002).

In summary, no pre-injury or injury predictors are significantly associated with return to work. But the process by which they affect return to work may be informative.

Post injury indicators of return to work in ABI

Indicators are factors related to the sequelae of ABI which indicate (rather than predict) the possibility of return to work. Indicators from the service provider's perspective are largely related to neuropsychological function and activities of daily living (ADL). As with predictors, the critical review of existing research does not indicate that basic cognitive function translates into better ability to return to work. However it may be possible that executive function is more reliable as an indicator than others (Table 2.3). Executive function would include divided and selective attention, concept formation, flexibility and planning.

Table 2.3: Critical review of Post Injury Neuropsychological Indicators associated with employment outcome (Ownsworth and McKenna 2004)

Neuropsychological indicators	***% = Percentage of studies significantly associating indicator with employment outcome. (n) = no. of studies which examined the indicator***			
	Papers rated Marginal n=31	Papers rated Acceptable n=14	Papers rated Commendable n=5	Level of empirical support
Estimated pre-morbid IQ	0% (2)	-	-	Low support and insufficient research
General intellectual or global cognitive functioning	50% (6)	100% (3)	-	Moderate support
Verbal or language functioning	50% (10)	0% (1)	-	Mixed findings
Perceptual or visuo-spatial ability	64% (11)	100% (2)	-	Moderate support
Memory functioning	56% (9)	50% (2)	-	Mixed support
Attention/processing speed	45% (11)	67% (3)	-	Mixed findings
Executive functioning	75% (8)	100% (2)	-	Moderate-strong support

Another way of exploring post-injury indicators is to look at quantitative measures of neuropsychological and daily living abilities. However a review of various tools and tests measuring these abilities reveals that ***almost every outcome measure that has been associated in one paper is not found to be associated in another*** (Table 2.4).

Table 2.4: Conflicting associations between various post injury outcome measures and employment outcome

Study	Outcome measures associated with return to work (RTW)	Outcome measures poorly associated with RTW
Utilizing neuropsychological measures to predict vocational outcome in a head trauma population (Ryan, Sautter *et al.* 1992) (Outcome was a good vocational evaluation rather than actual RTW) Descriptive study with 80 subjects		WAIS-R, PIAT, Trail making test A & B, the Grooved Pegboard, the Reitan- Indiana Aphasia Screening test, Beck depression inventory, Controlled oral word association test, Rey-Osterreith Complex figure Test.
Competitive re-employment after severe Traumatic Brain Injury (Cattelani, Tanzi *et al.* 2002). Descriptive study with 35 subjects	Length of coma & PTA WAIS-R & Cognitive function (Attention, orientation, learning and episodic memory) Behavioural function (defective and excessive) Age > 45	CT scan findings at admission Barthel score GCS (at admission) Changes in WAIS-R and neuropsychological scores
Factors influencing failure to return to work following traumatic brain injury(Greenspan, Wrigley *et al.* 1996) Retrospective study with 343 subjects (42% by proxy)	FIM score Graduated high school	Age Marital status Previous education and occupation Gender
Stability of employment after brain injury (Possl, Jurgensmeyer et al. 2001) Retrospective study with 43 subjects		Neuropsychological and (vs.) psychopathological problems
Prediction of employment status 2 years after traumatic brain injury (Ponsford, Olver et al. 1995). Retrospective multivariate study with 254 subjects	Mean GCS score Disability rating scale at admission Age > 40 Alcohol abuse	
Predicting return to work in traumatic brain injury using assessment scales (Rao and Kilgore 1992 October) Prospective study of 57 severe TBI admissions (67% returned to work)	Patient evaluation & Conference system (PECS) scale, Ranchos Los Amigos Cognitive functioning scale and DRS scores	

Table 2.4: Conflicting associations between various post injury outcome measures and employment outcome (continued)

Study	Outcome measures associated with return to work (RTW)	Outcome measures poorly associated with RTW
Acute predictors of successful return to work 1 year after traumatic brain injury: a multicenter analysis (Cifu, Keyser-Marcus et al. 1997) Retrospective study with 49 employed and 83 unemployed TBI subjects at 1 year follow-up	Some measures of: Severity of injury (Highest GCS, GCS at admission, Length of coma, Length of PTA) Function (FIM at admission, DRS at admission, discharge and change) Behaviour (Neurobehavioural Rating Scale –excitement, RLA at admission and discharge) Cognition (NRS delayed logical memory)	Other measures of: Severity of injury (Lowest GCS, Associated injuries, ICH) Function (FIM at discharge and change) Behaviour (Change in RLA score, NRS – energy, anxiety) Cognition (NRS -metacognition, cognition, immediate memory, Trail A/B, Pegboard)
Traumatic brain injury: factors predicting return to work or school (Ip, Dornan et al. 1995). Retrospective study of 45 subjects post TBI (another 18 were lost to follow up) and who could complete cognitive tests,	Age High school graduation Unmarried Alcohol Abuse Few sub-scores of cognitive tests (Performance WAIS-R, Trail-A, Non dominant Pegs)	Gender Education Type of profession Time since injury Severity of injury (Length of coma, GCS) Motor, speech, vision, hearing impairments. Cognitive tests (Verbal and full WAIS-R, WMS-R, Halstead-Rietan tests, Grooved Pegboard tests)
Neuropsychological Impairments, vocational outcomes and financial costs for individuals with Traumatic Brain Injury receiving state vocational rehabilitation services (Johnstone, Schopp *et al.* 1999) Retrospective study with 110 TBI subjects		WAIS-R WMS-R Trails A & B (processing speed)

Table 2.4: Conflicting associations between various post injury outcome measures and employment outcome (continued)

Study	Outcome measures associated with return to work (RTW)	Outcome measures poorly associated with RTW
Return to work for persons with severe traumatic brain injury: A data based approach to program development (Wehman, West *et al.* 1995) Review of literature and Retrospective study with 87 subjects	Motivated family Medical/health problems Layoffs or Poor job match Quality of work Severe neuropsychological or cognitive deficits Alcohol abuse	Previous Therapy services
Predictors and Indicators of work status after traumatic brain injury: a meta-analysis (Crepeau and Scherzer 1993) Meta-analysis with 41 studies reported lack of clarity because studies were too few and too heterogenous. Correlations described were moderate.	Global cognitive function esp. language deficits, attention and visuospatial processing Emotional disturbances Age > 60 Frontal or other damage on CT GCS admission & PTA>1 day Level of post coma activity Vocational rehab services	Age 45-60 Education Pre-trauma work status Irritability Family situation
Stroke Location is not associated with return to work after first ischemic stroke (Wozniak, Kittner *et al.* 1999). Prospective study of 143 stroke patients	White race Income > $15000 Barthel independence score Cortical signs at 7 days Younger age	White collar job GCS Motor strength score Aphasia at 7 days Right sided or supra/infra tentorial or lacunar or small cortical stroke Depression score
Indicators for return to work after stroke and the importance of work for subjective well being and life satisfaction (Vestling, Tufvesson *et al.* 2003) Retrospective study of 120 patients	Walking, white collar job and cognitive ability were more important than ADL independence, basic education and blue collar jobs	Upper secondary or tertiary education, Grip function, private sector or self employed, sex, civil status, age at stroke, working hours, job satisfaction

Glossary

WAIS-R = Weschler Adult Intelligence Score – Revised is a measure of functional intelligence as are Trail making , Grooved Pegboard, Rey Osterrieth, Halstead Reitan tests and PIAT = Peabody Individual Assessment. WMS = Weschler Memory Scale – Revised; a measure of memory.

PTA = Post traumatic Amnesia is a measure of severity of injury as are Rancho Los Amigos Scale and GCS = Glasgow Coma Scale.

Barthel score is a measure of independence of activities of daily living as is FIM = Functional Independence Measure and DRS = Disability Rating Score at admission and discharge.

Behavioural Indicators of return to work

Apart from the neuropsychological and cognitive variables, behavioural issues like interpersonal relationship skills, Metacognition (including insight or awareness of one's cognitive processes - referred to in the introductory chapter) or psychiatric issues like anxiety and depression are all important issues in employment but these are largely un-researched areas. It is felt that self awareness and acceptance can be critical turning points in rehabilitation (Ownsworth and McKenna 2004). The assessment of behavioural issues is difficult and has not been clearly classified. As seen in Table 2.5, there is insufficient research in the area of behavioural indicators of employment outcome.

Table 2.5: Critical review of Post Injury Behavioural Indicators associated with employment outcome (Ownsworth and McKenna 2004)

Behavioural, emotional & metacognitive indicators	***% = Percentage of studies significantly associating predictor with employment outcome. (n) = no. of studies which examined the indicator***			
	Papers rated Marginal n=31	Papers rated Acceptable n=14	Papers rated Commendable n=5	Level of empirical support
Interpersonal skills	0% (1)	0% (1)	-	Insufficient research
Emotional status	0% (2)	100% (3)	-	Moderate support
Post traumatic stress	-	100% (1)	-	Insufficient research
Self-reported symptoms	67% (3)	0% (1)	-	Mixed findings
Self-awareness	67% (3)	-	-	Mixed findings and insufficient research

The individual would be a rich source of information but unfortunately in ABI this research seems to be non-existent. Possibly it is felt that self reported symptoms are less reliable than functional status measures, especially as there is often associated lack of insight and distress or anxiety in individuals with ABI. But perceptions of the individual about return to work, behavioural and metacognitive issues are probably key pieces in the puzzle that we need to complete the picture and understand what

best correlates with successful return to work. But at present, both the critical review of post-injury neuropsychological and behavioural indicators of employment outcome and a review of papers using a barrage of quantitative outcome measures are inconclusive. Post-injury variables are therefore probably not good indicators of employment outcome or the key variable has still eluded researchers.

Social and Work related Indicators of return to work in ABI

Until now, the discussion of factors associated with employment outcome has been conceptually based on the medical model. The focus has been on factors associated with the ABI individual's needs or disability. The social and environmental issues relating to individuals with ABI will now be explored and this is conceptually based on the social model. The focus is on factors within the individual's environment which indicate employment outcomes. The afore-mentioned critical review has reported that despite several factors being studied, again, no conclusive picture emerges from the data on social and environmental factors. Research in this area is sparse but it is commonly agreed that the significance of social and environmental factors in returning to work is increasingly being recognised and that this is a critical area of research (Ownsworth and McKenna 2004) as can be seen from Table 2.6.

Table 2.6: Critical review of Injury Social and environmental indicators associated with employment outcome (Ownsworth and McKenna 2004)

Social environment indicators	Percentage of studies significantly associating indicator with employment outcome. (n) = no. of studies which examined the indicator			
	Papers rated Marginal n=31	Papers rated Acceptable n=14	Papers rated Commendable n=5	Level of empirical support
Litigation involvement	50% (2)	50% (2)	-	Mixed findings
Insurance status or source of funding	0% (1)	100% (1)	-	Insufficient research
Social support	100% (1)	-	-	Insufficient research
Employer or work environment variables	50% (2)	-	-	Insufficient research
Rehabilitation and vocational support services	67% (3)	100% (1)	-	Moderate support

Despite work related variables not being conclusively associated with employment outcome, the relationship of employer and work related variables to employment outcome are of particular interest and studies describe important factors like:

- *Type of job*: In stroke, return to work was shown to be better with white collar jobs rather than blue collar jobs (Howard, Till *et al.* 1985; Saeki, Ogata *et al.* 1995; Vestling, Tufvesson *et al.* 2003). A strong pre-injury work history was a strong predictor of return to work (Heinemann, Roth *et al.* 1987). However if the client is returning to a highly skilled job or if work re-entry is at a lower level than the pre-morbid job, these are associated with poor outcomes (Heinemann, Roth *et al.* 1987).
- *Economic disincentives*: An income of more that $30000 annually was a positive predictor of return to work (Wozniak, Kittner *et al.* 1999). The time at which return to work seemed to peak seemed to be associated with the period allowed by social security – around 18 months in a Japanese study (Saeki, Ogata *et al.* 1995). It was also noticed that the reason why 6 of 25 clients with brain injury did not return to work was because the disability or compensation incomes were in excess of the potential earned income (Haffey and Abrams 1991).
- *Work related skills*: These are skills like initiating a task without prompting or direction, responding to non-verbal cues, observing safety requirements and using compensatory strategies consistently. Their absence makes it difficult for a person to return to work (Fraser, Cook *et al.* 1997).

Employers' attitude and willingness to re-hire (Sale, West *et al.* 1991) has been insufficiently researched though this and family support are described as important factors in successful return to work (Abrams, Barker *et al.* 1991).

In summary, there are several issues to be explored in the areas of support from work place and community and behavioural and metacognitive issues. The individual with ABI needs to be asked regarding this. *Significant associations between employment outcome and individuals with ABI and their society have eluded researchers in the last 2 decades.*

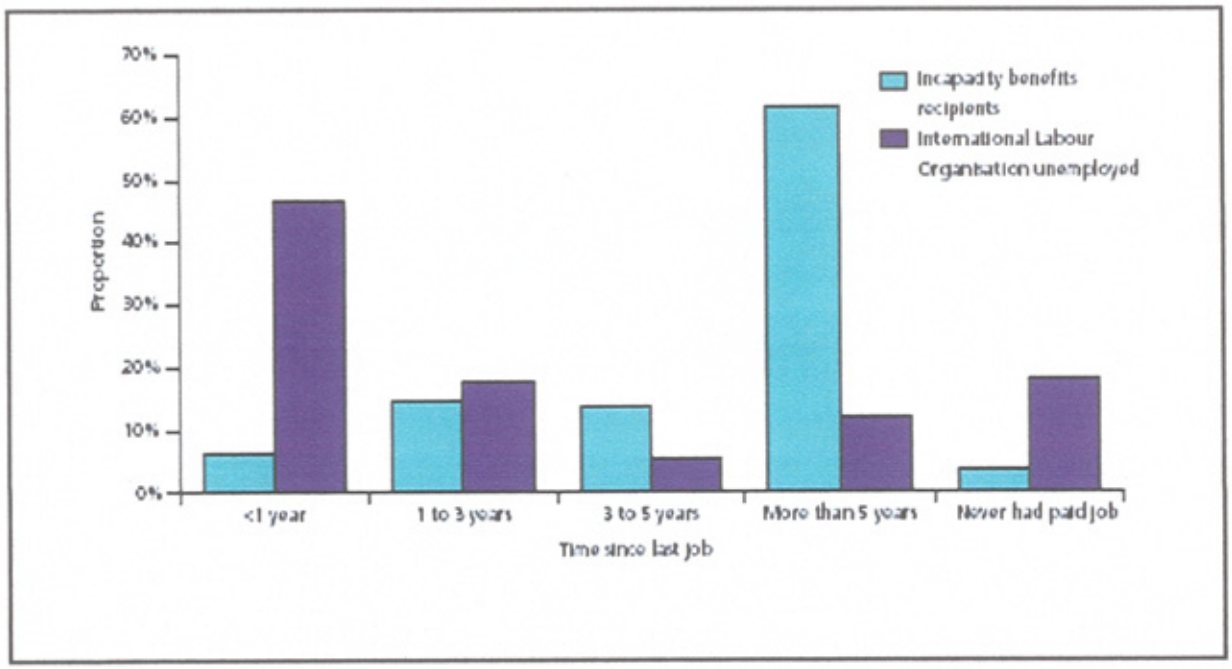
Return to Work in the General Population

Another area of research which has bearing on return to work in adults with ABI is the pathway of return to work taken by the general population.

Around 30% of the 2.7 million people of working age receiving incapacity benefit in the UK would like to return to work. Only a very small proportion of these recipients have severe disability e.g. only 0.7% of all claimants have stroke. The numbers with traumatic brain injury are not reported (DWP 2002).

Since 1999, the UK Department of Work and Pensions (DWP – previously DSS) has commissioned several research projects and publishes research reviews regularly (Green, Smith *et al.* 2000; Green, Connolly *et al.* 2001; Green, Marsh *et al.* 2001; DWP 2002). Most of the research in this area is largely descriptive statistics or qualitative data from surveys conducted on a New Deal vocational programme run by the Department of Work and Pensions called ONE. ONE offered a single point of entry into the benefits system to all unemployed people of working age who were working less than 16 hours a week. ONE provided at least one compulsory meeting with a personal advisor. Then it surveyed its clients in the pilot and control areas and, not surprisingly, found no significant differences to the programme. However in the process the vocational behaviour of the general population was understood very well. The highest proportion of people finding 16-or-more--hour-a-week jobs were job seekers on allowance (35%) as against the 'sick and disabled' category (25%) and lone parents (16%) (Green, Smith *et al.* 2000). In the first year of unemployment around 90% of them expect to return to work. Around 40% were still receiving benefits at the end of the year. Figure 2.1 shows that, unlike International Labour Organization patterns, nationally, the longer the period of unemployment, the less likely it will be that people return to work – around 60% of those on benefits have not worked for more than 5 years (DWP 2002).

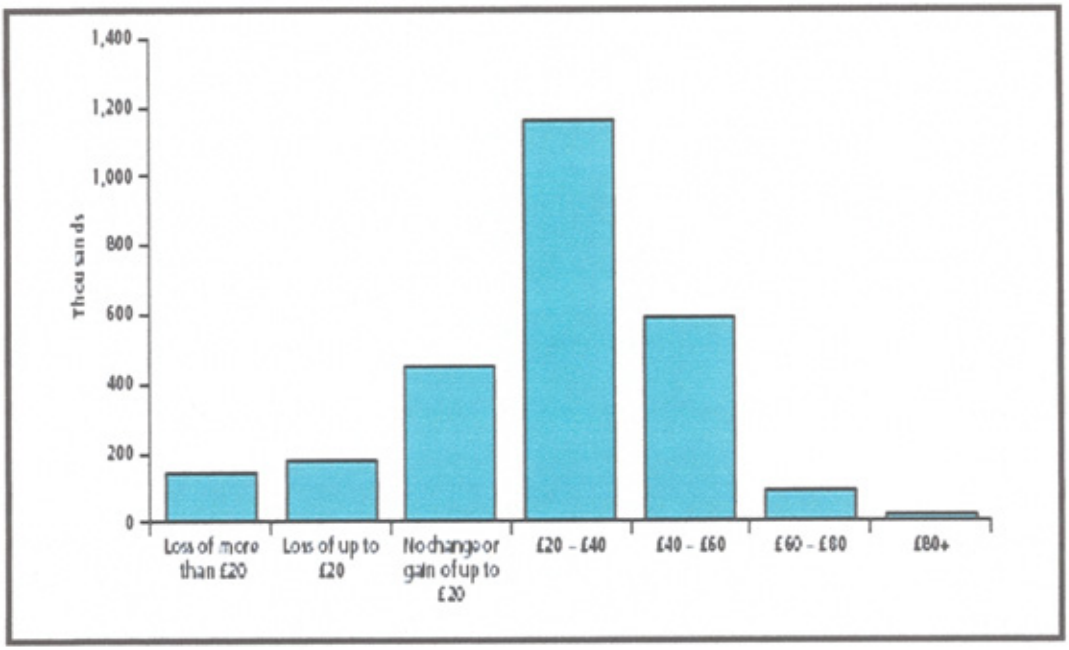
Figure 2.1: Length of time since last job



Source: Pathways to work – Helping people back into employment, Secretary of state for Work and Pensions, November 2002.

In addition, financial disincentive plays a role in return to work. Motivation to return to work was reduced by a poorly planned benefits programme. Most incapacity benefit recipients either lost income or gained only £40 a week if they returned to a 30 -hour-a-week job at minimum wage as is illustrated in figure 2.2 (DWP 2002):

Fig 2.2: Gains to be realised by incapacity benefits recipients moving into work of 30 hours a week at the National Minimum Wage



Source: Pathways to work – Helping people back into employment, Secretary of state for Work and Pensions, November 2002.

Prolonged unemployment seemed to have persisting effects on health and socio-economic status (Wadsworth, Montgomery *et al.* 1999).

Gender differences have been noticed in the general population returning to work. Men preferred unsatisfactory employment to unemployment. Women coped with unemployment better (Theodossiou 1998) and preferred it to unsatisfactory employment (Winefield, Tiggeman *et al.* 1991).

In addition the unemployed have perceptions about work which affect the process of return to work. There has been an associated loss of self esteem, increased anxiety, more illness and medical intervention (Linn, Sandifer *et al.* 1985). Though there was more self-blame and wishful thinking in the unemployed, this was related more to mood disorders (Matoba, Ishitake *et al.* 2002) or anxiety and less to depression (Grossi 1999).

Responses were obtained from ONE clients regarding perceived obstacles to unemployment among all incapacity benefit recipients. The themes that were reported centred around health, finances, job opportunities, confidence and skills and fear of discrimination. The prominent themes were reported around the areas of finding work, financial disincentives and confidence to work. These are listed in Table 2.7 (DWP 2002).

Table 2.7: Obstacles to work perceived by incapacity benefits recipients (DWP 2002)

Obstacles to work identified by incapacity benefits recipients	Looking for work	Would like to work – but not looking
Health factors		
I'm unlikely to get a job because of my health problems	34	59
Finding work – availability of jobs		
There aren't enough job opportunities locally for people like me	50	26
It's difficult to find the kind of work that would suit me	37	21
Finding work – confidence and skills		
My confidence about working is low	49	41
I haven't got enough qualifications and experience to find the right work	17	20
Financial considerations		
I have worries about managing financially until the first pay day	28	16
I have worries about managing financially while in work	18	13
I have worries about paying the rent or mortgage while in work	11	11
I think I would be worse off financially if I started work	13	10
I have worries about leaving benefit	15	11
Discrimination		
Other people's prejudices make it difficult for me to work	3	9
Others		
I couldn't afford the cost of transport to get to work	7	11
Travelling to work would be difficult	8	16
None of these	8	14
Unweighted base	72	222

Base: All respondents who made a claim for benefit and were not in paid work at interview. This figure was not weighted to account for non-response percentages in both groups.
Respondents could give more than one answer so columns do not sum to 100.

A larger proportion of responses are related to finding work. The report attributes this to a large proportion of the group being "detached from the labour market". Around a third of them have never ever worked. All the other processes like a lack in confidence, financial disincentives or health difficulties further widen the detachment. The government reports then advocate that apart from restructuring benefits programmes, the approach of improving work skills and developing confidence would be the best way forward.

These perceptions in the general population are a good indication of the perceptions of individuals with ABI in the process of return to work.

In summary, though vocational programmes offered to the unemployed in the general population have not made a significant difference to the process of return to work in the community, they have improved our understanding of unemployment. The importance of building up self esteem and confidence, decreasing financial disincentive and reducing time period of unemployment after the first job loss have been highlighted in the general population.

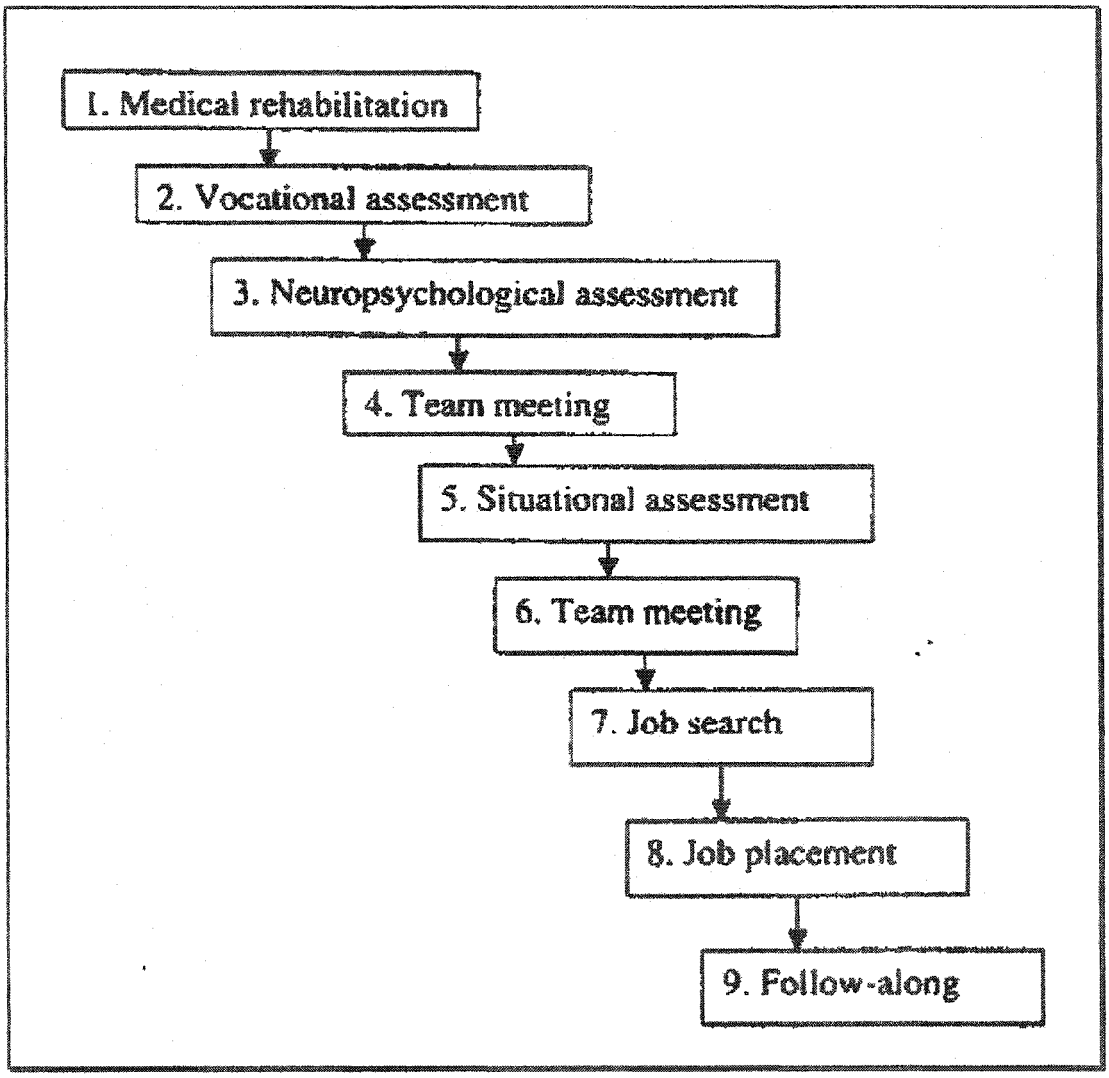
Conceptual models of return to work

While the factors relating to return to work are still being evaluated, the process of vocational rehabilitation has been a well trodden path. Thus experience has resulted in several proposed conceptual models of the process of return to work.

The two published conceptual models (Figures 2.3 and 2.4) are very similar but emerge from experience rather than evidence. Both propose a holistic and long term involvement with the individual. The interaction of various disciplines is also a requirement. Both are faithful to the principles of vocational rehabilitation and the practice of supported employment programmes affirms their veracity.

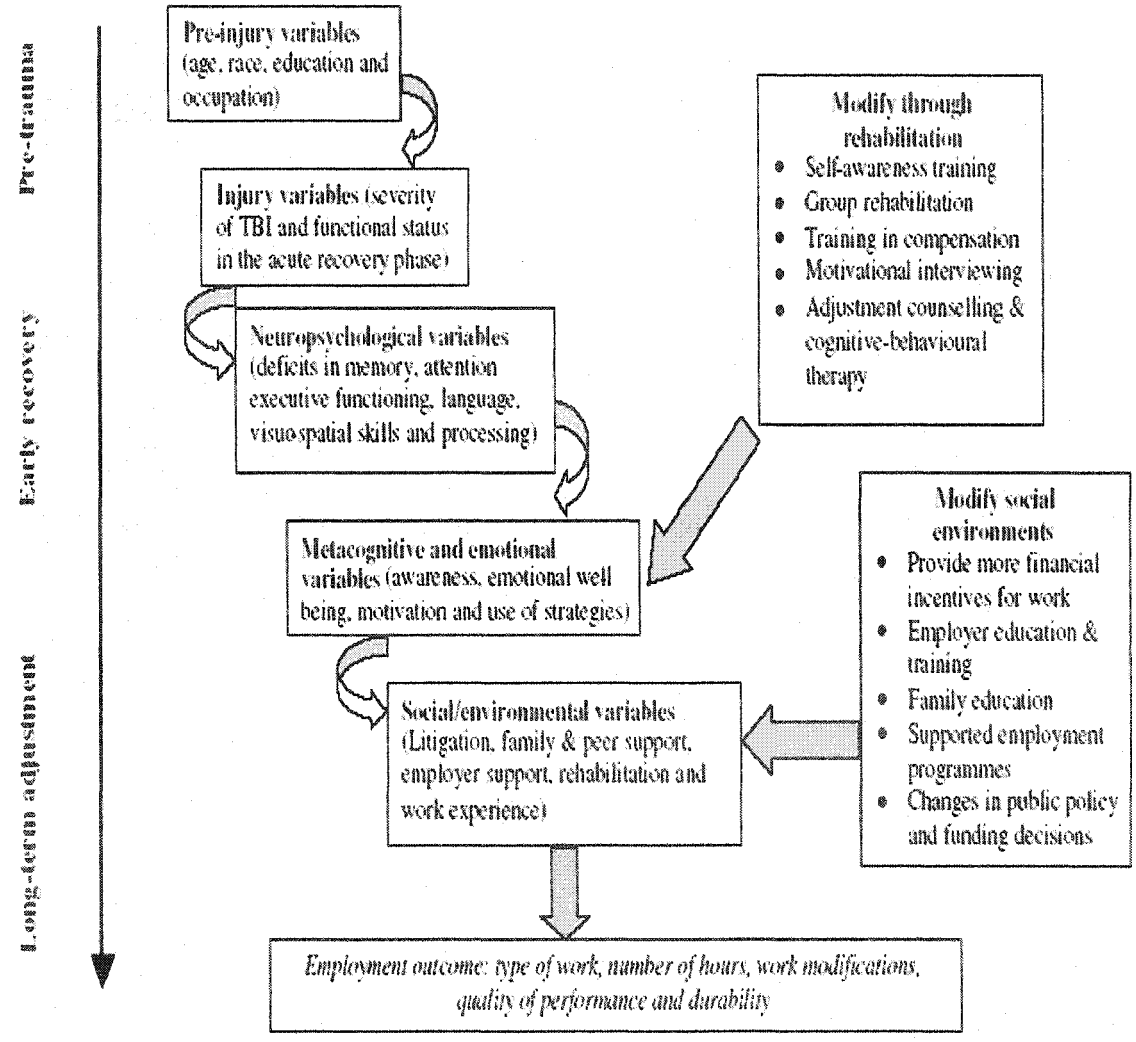
The first model is based on the temporal process of rehabilitation and does not suggest a temporal profile for the follow up period. The steps in this model only include the service provider interactions with the person with ABI as seen in Figure 2.3.

Fig 2.3. The Brain injury assessment model (Vandiver, Johnson et al. 2003)



The next model was proposed, rather surprisingly, after a critical review of research which concluded that the association between employment outcome and the very variables proposed in the model were either conflicting or inconclusive. However this model did address the impact of advocacy, social and environmental issues and the need for supported employment. However long term follow up is not specifically included as seen in Figure 2.4.

Figure 2.4. A conceptual model of factors related to employment outcome and interventions for improving employment potential following traumatic brain injury. (Ownsworth and McKenna 2004)



Though this second model ends with the employment outcome, it is often the case that the process needs to be ongoing (described as follow-along in the first model).

Thus, in both conceptual models, the temporal sequence of events is linear and the impact of feedback is not included in either model.

SUSTAINING EMPLOYMENT

The deficiencies of conceptual models of return to work highlight the lack of long term follow up data. Therefore this last section reviews literature of the long term process of employment. First the process of sustaining employment in the general population is reviewed to give a broad perspective on the specific issues of long term follow up in ABI.

Sustaining Employment in the general population

A commission of the Department of Education and Employment has reviewed the concept of employment sustainability for the government in an effort to improve the employment conditions of those leaving job seeking benefits in the UK. This commission defined employment stability as the "*maintenance of a stable or upward employment trajectory in the long term*".

Sustaining employment was described as a multifaceted area and not merely the duration of the job (*job tenure* or stability) but also the ability to hold on to a job even when circumstances changed (*job retention*) and progress to better jobs (*career advancement*) (Walker and Kellard 2001).

Internationally, the general trend of job stability in terms of actual tenure has been decreasing over the decades. There is no specific UK data available but the US Employment Benefit Research Institute reports that an average job tenure is between 5-10 years (HRM-Guide 2001). A decline over time for males was reported as seen in table 2.8.

Table 2.8 : Median tenure of jobs for men in the US is decreasing (HRM-Guide 2001)

Age ranges for males	Median tenure of job in 1983 (years)	Median tenure of job in 2000 (years)
35-44	15.3	10.2
45-54	12.8	9.5
55-64	7.3	5.4

There were variations for women (tenure rising from 1951) and public sector employees tended to have job tenures which were twice as long as private sector workers (HRM-Guide 2001).

The Department of Work and Pensions Research Report No.126 presented some exploratory data using a Logit model to predict the probability of outcome in each group which was uncontrolled for local employment opportunities and local employment rates. This exploratory multivariate analysis suggested that having *worked in the previous 2 years* made it 2-3 times as likely to sustain employment for lone parents and those who were on job seekers allowance. Sick and disabled clients were 8 times as likely to be in work if they had worked in the previous 2 years. Previous education was also suggested as an important factor in sustaining employment with it being more than around 2 times as likely for ONE clients to have sustained employment if they had *qualifications at A level* and above. Having a partner was proposed to have a beneficial effect on sustaining employment. Factors reported to affect sustaining employment adversely were having dependent children, being a tenant rather than a house owner and having long standing disability. Those over 50 and ethnic minorities were at a disadvantage as well (Green, Smith *et al.* 2000).

However it must be emphasised that most of the research into this topic is at the exploratory stage.

Sustaining Employment in ABI - The Return Loop Syndrome

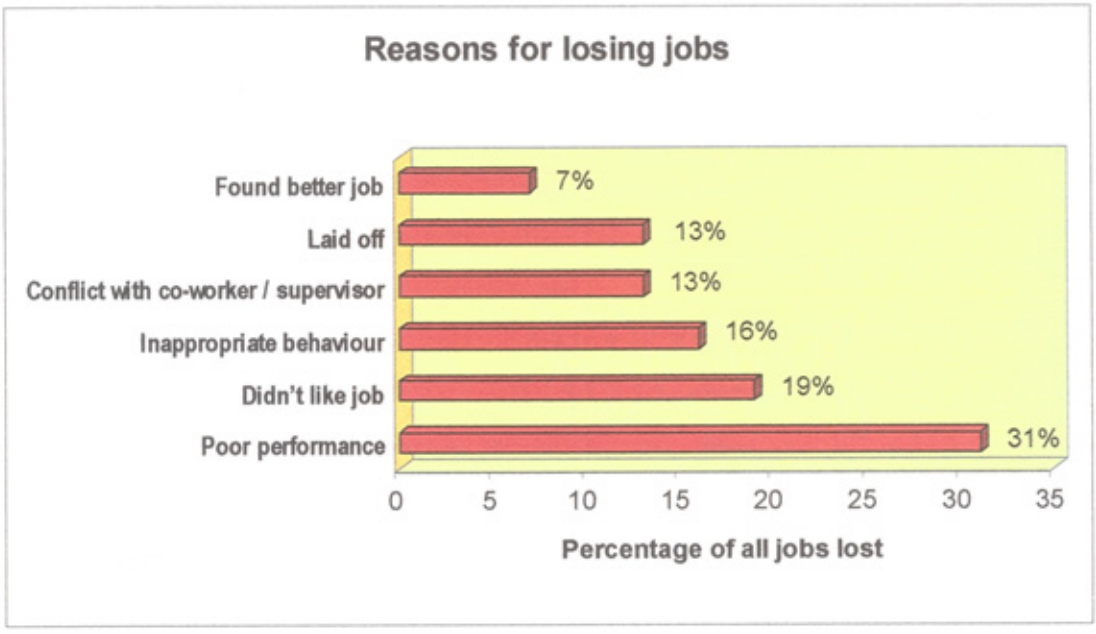
Sustaining employment in ABI was discovered to be a problem after return to work. In the traditional vocational programmes, around 30-50% of those who returned to work could not sustain their jobs. Without SE, around 27% are unstably employed and 39% unemployed at three years. If a person did not work in the first year post injury, they were even less likely to be employed stably, if employed at all, at two and three years (Ip, Dornan *et al.* 1995; Greenspan, Wrigley *et al.* 1996; Sander, Kreutzer *et al.* 1996; Possl, Jurgensmeyer *et al.* 2001; Cattelani, Tanzi *et al.* 2002; Kreutzer, Marwitz *et al.* 2003; Tyerman and Meehan 2004).

Though a significantly larger percentage of people with ABI return to work with the Supported Employment approach, job coaches discovered that sustaining employment over the first and second year after return to work was a problem. Around 26% to 27% of those in SE programmes required a second placement (Sale, West *et al.* 1991; Kreutzer, Marwitz *et al.* 2003). Around 69% of those who lost their jobs did so in the first six months (Sale, West *et al.* 1991). This is such a common feature in vocational rehabilitation, that it has been coined the 'Return Loop Syndrome' (Parenté, Stapleton *et al.* 1991). Thus, the Return Loop Syndrome is characterised by successfully coached clients returning to the vocational programme within a 5-year period having either left or lost their jobs.

Factors causing job loss

In the Work Re-entry Programme as well, data on 67 people who had lost their jobs showed that around 75% had lost their job once, less than 20% had lost their jobs twice. Based on the termination forms filled out by their clients they reported that the factors associated with job loss were as in Figure 2.5 (Abrams, Barker *et al.* 1991).

Figure 2.5: Reasons for losing jobs as reported by clients



There was an exploratory study of job loss after returning to work through an SE programme in Virginia, USA using qualitative methodology(Sale, West *et al.* 1991; Ponsford 1995). Job coaches in this study reported that most job losses (69%) occurred in the first six months and more than 75% for multiple reasons. Factors for job loss were broadly categorized into the following factors:

- **Interpersonal issues**: Around half of the job losses were caused by dysfunctional interpersonal relationships. These included misinterpretation of social cues, interpersonal conflict and inappropriate verbalization.
- **Substance abuse / criminality**: In around a third, substance abuse or criminal activity contributed to job losses.
- **Work related issues**: Problems with the employment setting including job match, upward or lateral mobility, job routines and work place culture.

Others have also reported economic disincentives (Haffey and Abrams 1991) causing job loss. Pre injury predictors of ability to sustain employment have included age, education and marital status. Some Injury Predictors of job stability have been suggested such as length of unconsciousness and Disability Rating Scores at one year (Kreutzer, Marwitz *et al.* 2003).

It is unclear why people lose jobs and some proposed reasons are:

- **Upward mobility**: A client who returns to work and sustains employment successfully develops confidence and self esteem. This results in an offer of promotion often with the expectation of continued success. However as demands increase, the client finds it difficult to match his abilities with the job. The poor match between abilities and demands in the promoted position is not recognized and therefore ways of compensating for this are not put into place and the client faces job loss.

- **Change in job duties**: A client who is able to stick at a job starts to experience change in environment, demands, managers or co-workers. These changes cause stress and challenge coping abilities.

- **Loss of support system**: As the client becomes more engrossed in the vocational environment and the job coaching contact is slowly withdrawn by the programme, the client slowly loses contact and support of the peer interaction, therapy sessions and feedback. The sense of loss of support could be countered by keeping follow up open ended as has been emphasised in previous sections. The follow up team could be more flexible and offer more intervention based on appropriate follow up. This would mean that job coaches would need to be trained in trouble-shooting and crisis management skills (Parenté, Stapleton *et al.* 1991).

- The Work Re-entry Programme reported that 57% of their clients received counselling, 57% were supported by their employers, 48% by employer support groups and 66% by follow up from the programme. Despite this they reported that they had difficulty sustaining employment and planned to add an "employment retention specialist" to their programme to co-ordinate follow along services (Abrams, Barker *et al.* 1991).

- Other approaches to help individuals with ABI to sustain employment include Employee Assistance Programs and Peer interaction sessions. Natural supports in the work place have been used. This might include training, supporting and advising co-workers or employers to act in a mentors' role to improve job stability (Brooke, Inge *et al.* 2003).

SUMMARY

Most of the studies about SE programmes in ABI are quantitative in methodology and describe the short term outcome or factors associated with return to work rather than the longer term outcome of sustaining employment or job stability. Due to small numbers available to study, high variability in the population studies, a lack of validated outcome measures and a poor understanding of hypotheses, several of these studies contradict each other or have methodological lacunae. Studies have failed to consistently identify predictors or indicators of good outcome. The perspectives of others involved in the process of vocational rehabilitation and indeed the person with

ABI have not been adequately considered. Issues crucial to the person with ABI, especially behavioural and metacognitive aspects, have not been adequately researched despite being recognized as important. Conceptual models for return to work do not include longer term issues relating to sustaining employment.

The factors associated with return to work in the general population in the UK are common to anyone returning to work and mostly centre around themes of health, employment, psychosocial and economic issues.

Research into the long term sequelae after return to work is sparse. It is reported that individuals with ABI who return to work find it hard to sustain employment. One exploratory qualitative study using Grounded Theory has some information on the long term issues of sustaining employment. The issues identified by job coaches in this study centre around themes of interpersonal relationships, employment issues and substance abuse. This area of research is a platform for the current research project.

CHAPTER 3

AIMS AND OBJECTIVES

AIM:

To develop a conceptual model of how and why individuals with acquired brain injury who have been supported by a vocational rehabilitation programme are able or unable to sustain their jobs.

OBJECTIVES:

1. To obtain vocationally related perspectives of:
    a. Individuals with acquired brain injury who have been supported by a vocational programme and are unable to sustain their jobs.
    b. Individuals with acquired brain injury who have been supported by a vocational programme and are able to sustain their jobs.
    c. A member of their family
    d. A person from their work place (co-worker / manager / employer)
    e. A key member of their vocational programme
2. To relate all these perspectives to ability, cognitive, behavioural and work characteristics in each of these individuals with ABI.
3. To explore the process by which these relationships interact with sustained or ill-sustained employment within the framework (thematic approach) of previous research.
4. To explore the implications of these relationships with a view to developing a conceptual model for sustaining employment.

CHAPTER 4

METHODOLOGY

A flexible qualitative research design was chosen to study sustained employment in ABI. The eclectic design was based on the multiple case study approach and used the structure of Framework analysis and analytical software. This chapter defends the choice of this design and its application to this research project. It also describes the methods adopted to improve the design's trustworthiness and transferability.

RESEARCH DESIGN

Critical Realism

Almost all of the previous studies in vocational rehabilitation were quantitative studies which expected the general laws of sustaining employment to be based on quantifiable facts which were free from values. Most have not met the ideal requirements of quantitative research. None of these studies have been able to achieve the rigour of a randomised double blind control trial (Crepeau and Scherzer 1993; Ownsworth and McKenna 2004). Many have not been able to study sufficient numbers. Further, multiple, "soft" variables and a wide variation between them have confounded interpretation. A lack of sensitive and specific tools, a poor definition of

outcomes and a minimal or absent follow up have limited the applicability of quantitative approaches. Thus, reviews of previous research have shown that a purely positivist approach was not able to provide a clear understanding of sustaining employment.

A randomised control trial to evaluate efficacy is not possible for ethical reasons – how can one ask a person with brain injury to accept 2-3 years of placebo rehabilitation? (Wehman, Kreutzer *et al.* 1990). The only alternative is to actually look at large numbers but this is difficult in practice as:

- Employment programmes are not standardized (Thornton, Banks *et al.* 2005) as will be required in multi-centre trials.
- Individuals with ABI have highly variable and non-homogeneous characteristics.
- Selection criteria will eliminate potentially important characteristics in this highly variable population under study.
- Outcome measures are still in the process of evolution.
- There are very few vocational rehabilitation programmes for ABI.

Thus, it has not been possible to provide more quantified evidence to answer the fundamental question of whether supported employment is useful or not. This inability to discover significant associations using quantitative methodology has been reflected in around 85 papers published between 1980 and 2004. With wide variability of subjects, unavailability of a control group, small numbers and very few validated tools, quantitative research in this area has not been able to produce definitive results and has, in fact, produced contradictory findings. The exception is the 'econometric' approach. The econometric approach used economic parameters to show that supported employment yields more cost-effective results (Dean, Dolan *et al.* 2003). But apart from clinching the financial efficacy question, at the present time, using quantitative methodology to identify factors influencing issues relating to sustained employment may not provide meaningful or clinically useful answers.

An alternative is to explore the qualitative perspectives of all the people involved in the process. Their reflections of their experience might help us find out what caused them to keep or lose their jobs. It might be possible to develop a conceptual model of

sustaining employment using interpretative analysis rather than statistical analysis. This is because the data would be textual rather than numerical. Textual data will need to be analysed by identifying topics in text and looking for explanations, relationships or associations within these topics. Thus themes will emerge from the textual data which might supplement the general (quantifiable) laws with values and subjective experiences which help us understand the process of sustaining employment. Behaviours, lived experiences and settings from various perspectives could be explored with an open, "discovery" attitude rather than a focussed, "eliminatory" approach (Robson 2002).

The review of literature has demonstrated that our exploration of sustained employment after vocational rehabilitation has not been sufficient to provide a clear understanding of what, how or why things are happening to individuals with ABI. The qualitative approach is the most suitable approach to combine exploration and in-depth analysis which is lacking from the current body of knowledge on vocational rehabilitation in ABI. Therefore it was decided that the research design would include a philosophical shift away from pure 'positivism' which expects general laws to be governed by quantifiable facts which are free from values. However, there are a number of studies which have measured variables by quantifying them in the literature (Crepeau and Scherzer 1993; Ownsworth and McKenna 2004). These studies are witness to the existence of quantifiable laws. Thus, a pure subjectivist approach which believes that reality is only based on our values and experiences would be dissonant with existing research. Thus a 'critical realist' approach was adopted. The 'critical realist' approach acknowledges 'positivism' but also agrees that we use values and subjective experiences to understand the facts and processes of the world around us (Robson 2002). It would provide the most appropriate philosophical underpinning to study the topic of sustaining employment in those with ABI.

The decision to choose qualitative methodology for this study is strengthened by the fact that there was one exploratory study done in the past using qualitative research (Sale, West *et al.* 1991). This study produced new information relating to the process of sustaining employment. It used the qualitative method of grounded theory to explore a framework of themes based on the perspectives of job coaches. The

exploratory themes published by this study were not reported in all previous studies on the topic. This study demonstrated the value of the critical realist approach.

Philosophically, critical realism is a promising step forward because

- It allows discovery and exploration of themes
- It opens up processes and motives behind these themes, promoting an understanding of not only what occurs, but why it occurs.
- It does not seek to homogenise variability but rather celebrate it (Sale, West *et al.* 1991).

Therefore, the research project was designed to use a qualitative approach based on the philosophical underpinning of critical realism.

The Multiple Case Study approach

There were several ways of using qualitative methodology to explore thematic information - the commonest being Case study, Grounded Theory, Ethnography, Phenomenology and Narrative Analysis. Phenomenology and Narrative analysis are subjectivist approaches i.e. they believe that the truth is experienced only through experiences and values and not through general laws governed by quantifiable facts (Robson 2002). Thus these two approaches were not considered as they would be in dissonance with current vocational rehabilitation practices and philosophy. Ethnography describes groups based on observations and records and is based on cultural anthropology. The basis of the approach is first hand observation through fieldwork (Robson 2002). However, the time available to the researcher was not conducive to the use of an ethnographic approach. Grounded Theory is a rigorous approach using thematic analysis to assign meaning to text units in an iterative way, always based ("grounded") in the textual data. Grounded Theory acknowledges that reality is not just about quantifiable facts but also multilayered and constructed from our perceptions (Robson 2002). It provides a systematic approach and a definitive end point when no further themes emerge from the data (saturation). Some proponents of Grounded theory propose that one should not start with preliminary ideas but with a

blank slate. However the prescriptive nature of application of the initial grounded theorists made it a less flexible choice than Ethnography or Case study approaches (Charmaz 2003). Moreover the previous experience of the researcher in vocational rehabilitation excludes the possibility of approaching the subject with a blank slate.

The **Case Study** approach, though often stereotyped as weak, can be both a qualitative and a quantitative approach. Its flexibility allows *description* (answers how?), *exploration* (answers what?) and *explanation* (answers why?). Unlike an experiment, the explanatory question (why?) in a case study can be answered without requiring control of events. This is because a case study allows the flexible use of evidence from interviews, tests, quantitative and qualitative observations (Yin 2003).

The case study approach is both a strategy and a flexible research design. The case study approach has been defined by Yin as "*an empirical inquiry*

- *which investigates a contemporary phenomenon*
- *especially when the boundaries between the phenomenon and context are not clearly evident and*
- *when there are more variables than data points*[1]
- *and therefore relies on multiple sources of evidence which need to converge in a triangulating manner*
- *and benefits from prior development of theoretical propositions to guide data collection and analysis" (Yin 2003).*

Several deficiencies in the existing research on sustained employment are addressed by the case study approach. The case study has the ability to look at several, highly variable and hitherto vaguely associated factors. It can source information from all stakeholders. It can analyse multiple forms of data. It can build on existing qualitative data on the subject (the previously mentioned exploratory study using grounded theory which had identified broad themes) by taking the magnifying glass to these broad categories to see if there are ways of identifying the process of sustained employment.

[1] Data points are units of analysis e.g. a single case study or a set of case studies or a contextual set like all employers from all the case studies.

The case study allows a flexible but focussed approach to data collection. There are several stakeholders involved in sustained employment in ABI whose perspectives are valuable. The Case Study design allowed an in-depth study of the perspectives of various people involved such as:

- Employed and unemployed individuals with ABI who have completed at least a year following the vocational programme offered by Rehab UK (S).
- Their chosen family member (F)
- Their chosen co-worker or line supervisor (E)
- Their job coach or key worker in Rehab UK (R).

Thus, the case study approach offered flexibility with in-depth study of multiple units of analysis. It was chosen as the overarching method for this research project.

Purposive selection

In a multiple case study approach, a relevant contextual theory or variable is used to choose subjects for analysis. Subjects would then be representative of the process being researched within that context or for that variable. Case studies rely on 'Analytical Generalization' rather than statistical generalization (Yin 2003). This process of selecting subjects with the specific purpose of improving representative-ness in the study is called Purposive selection.

In addition, *Purposive selection* can be used to improve transferability (or generalizability) of the findings in research. It has been suggested that the term 'transferability' is more suited to qualitative research as the term generalizability has come to mean a statistical 'fit' between the sample and the population from which it has been extracted. Transferability suggests that the processes discovered in qualitative research can be expected to replicate themselves in similar circumstances. Purposive sampling makes the data more 'information rich' for the topic being researched (Denzin and Lincoln 1994). So it was the method of choice for the selection of participants in this project.

There are several types of Purposive Sampling:

- *Extreme or Deviant Case Sampling*: This is used to select subjects who represent the extreme example of the topic being researched.
- *Intensity Sampling*: This is used to select subjects who are experts in the topic being researched.
- *Maximum Variety Sampling*: This is used to select a heterogeneous sample of subjects based on their commonality of experience in the topic being researched.
- *Critical Case Sampling*: This is purposive selection of subjects who have experienced the critical event in the research topic that may be generalised to other situations.

In this study, a two stage purposive sampling process was adopted. In the first stage the purpose was to obtain a representative sample with a heterogeneous mix of a variety of combinations based on age, family support and type of ABI to ensure that all age groups, types of ABI and people with varied family support were represented in the selection process. The best suited purposive sampling technique for this first step was **Maximum variety sampling** which would provide a heterogeneous selection from the representative sample. Thus,

1. The representative sample consisted of interviewees who had experience with employment after vocational rehabilitation for ABI.
2. A heterogeneous selection of subjects was made based on age, family support and type of ABI.

There was a tilt in this sample towards men of working age. This is a recognized factor in brain injury research and is seen in the population of those accessing vocational rehabilitation services with Rehab UK. Therefore this tilt towards men will transmit to the research project. However, rather than being a confounding factor, this is true in real world clinical situations in both main subgroups of ABI – strokes and traumatic brain injury (Hillier, Hiller *et al.* 1997; Bruns and Hauser 2004; Medin, Nordlund *et al.* 2004). From this heterogeneous sample of around 40 individuals, cases had to be selected based on critical, extreme, unique, typical, revelatory or longitudinal features (Yin 2003). Previous research had identified several factors which could possibly influence outcome. It was felt that pre-injury characteristics had to be used in selection as purposive selection of post-injury factors would be pre-

emptively judging some of the very variables that were going to be researched. Some pre-injury factors (no known ongoing substance abuse and possibly motivation to return to work) were already included as a result of the selection criteria of the Rehab UK programme. Other pre-injury factors which could influence sustained employment were pre-injury education and pre-injury employment. I wanted to obtain perspectives not only from those who had a productive pre-injury employment and appropriate education for the job, but also from those who were either unemployed or had found it difficult to keep a job as well as those who did not have education appropriate to their pre-injury job. To accommodate these two factors as well as the two major outcomes of sustained and ill sustained employment, **Critical case sampling** (selection of examples that are significant for the identification of critical incidents) was then used on the list of subjects who had been selected by maximum variety sampling and eight clients were chosen i.e. four combinations of the two factors in two matrices. Thus four people with ABI who had sustained employment and four who had not been able to sustain employment were selected as shown in Table 4.1.

Table 4.1: Matrix of case studies selected using critical case sampling

	SUSTAINED EMPLOYMENT			POORLY SUSTAINED EMPLOYMENT	
	Good pre-injury work history	Poor/no pre-injury work history		Good pre-injury work history	Poor/no pre-injury work history
Appropriate Pre-injury Educational experience	S1 **(48MD)**	S8 **(23MS)**	Appropriate Pre-injury Educational experience	S4 **(50MD)** **Pilot case study**	S2 **(34MS)**
Inadequate pre-injury Educational experience	S7 **(49FM)**	S3 **(25MS)**	Basic Educational experience	S5 **(45MD)**	S6 **(30MS)**

Exchanged later

Key: S# = Code name for each individual with ABI; Number =age; M = Male; F = Female; D = Divorced; S = Single; M = married.

Interestingly at the end of this process of purposive selection, two other methods of purposive selection were also found to be true.

- **Extreme case selection**: S3 and S4 were assigned as extreme cases as their pre-injury characteristics would not fit the expected outcome at all (a person with poor pre-injury education and work history was not expected to sustain employment, neither was a person with good pre-injury characteristics expected to lose his job).
- **Intensity sampling**: This is built into each case as job coaches (experts in their field) were being interviewed in each of the cases.

There were several practical issues which arose during the process of purposive selection. When, at the end of the selection process based on Rehab UK documents, the people with ABI were contacted, it was discovered that status of sustained employment of two subjects (S3, S6) had changed since their last documentation, but as it happened, they were neatly exchangeable within the matrix as seen in Table 4.2.

There were 32 interviews planned (eight case studies with four interviewees each) but two interviewees dropped out after consenting to take part. One was a line manager who dropped out as his company would not permit taped interviews and the other a family member who had second thoughts about participation. An interesting ethical-methodological dilemma ensued and was resolved when the researcher made a consensual decision with his guides, the concerned Job Coach, and the family member of the person with ABI not to interview a co-worker even though the individual with ABI had consented to the interview. The co-worker concerned was also line manager and employer and he was not interviewed because he was not aware of the individual's previous ABI and vocational rehabilitation. This could have potentially affected the future employment as a job reference was being requested at the time for a new job that the person with ABI had just obtained. Of the remaining 29 successfully interviewed, only one family member could not return respondent validation as he was very busy but promised to get back if he had anything to change or edit in the transcript.

But overall, several challenges within existing research (Guba and Lincoln 1994) were addressed in this research project:

- **Context stripping**: The factors which might be contributory might have been excluded e.g. substance abuse has a very strong negative impact on return to work. However many studies exclude those with substance abuse, thus stripping the study of a very important contextual factor which has a major impact on outcome. Once stripped, the reasons for substance abuse - which may have bearing on outcome – are equally ignored. If factors affecting sustained employment are to be clearly identified, it will be necessary to take each individual studied in their full context. To address this challenge it was decided not to have exclusion criteria based on ABI or vocation and, in fact, a few of the clients selected had problems with alcohol and motivation even after returning to work.

- **Exclusion of meaning and purpose**: When a hypothesis is being tested, the meaning or purpose behind the hypothesis is often excluded. Usually in quantitative studies, only objective pre-determined outcomes are considered. However, in the case of sustaining employment after brain injury, there are important issues like, for example, motivation and insight which might reveal themselves only when delving into meaning and purpose. If factors affecting sustained employment are to be clearly identified, it will be necessary to include meaning and purpose i.e. to allow the reasons or processes relating to sustained employment (e.g. study motivation and insight) to emerge. Thus the interview was semi-structured to give the interviewee an opportunity to choose topics to discuss within the interview.

- **Dysjunction of "outsider" theories to local context**: "Outsider" (etic) theories are less likely to detect contextual, local "insider or emic" factors. However, in an attempt to generalize results of research, these factors are usually named and set aside in the quantitative approach. If factors affecting sustained employment are to be clearly identified, it will be necessary to include local factors and their impact on the subject, even if that decreases the generalization of data. To allow the researcher to pick up insider factors, two stage purposive selection was used to include a "maximum variety" of cases as well as critical cases.

- **Inapplicability of general data to individual cases**: In the quantitative approach, there is an attempt to "box" individuals into various groups in an attempt to study

a pattern. If factors affecting sustained employment are to be clearly identified in a situation where each individual is different from the other, the interaction between the person's individuality and outcome will have to be interpreted case by case. This was addressed by including a multiple case study approach (rather than multiple examples within a single case study) and using a case by case analysis technique.

- **Exclusion of the discovery dimension in inquiry**: The quantitative approach works on a null hypothesis. The null hypothesis is usually based on one existent fact and supporting or disproving it improves the body of knowledge. However, when faced with uncertain or insufficient factual evidence, a rigorous process of exploration is more appropriate than an empirical exclusion of various null hypotheses. If – or when – exploration results in discoveries, these discoveries might then be evaluated using quantitative methods. A flexible and eclectic approach avoided 'methodolatory'. Also the Grounded Theory principle of being grounded in the data was adopted through the use of software which was based on its precepts.

Triangulation

Triangulation is the process of obtaining more than one perspective to research data. Triangulation helps by making the data more trustworthy and therefore increases validity. The objectivist basis of scientific knowledge is to be able to replicate the study. In the relativist traditions, this has been less important as scientific facts are viewed as a product of social and historical factors (Denzin and Lincoln 1994). In the critical realist approach, these two opposing beliefs are integrated. This has resulted in criticism that objectivism has been diluted and that the resulting research process has neglected issues of reliability and validity (Robson 2002). This has been compounded by the use of alternative terms for reliability and validity in qualitative circles i.e. Transferability and Trustworthiness. But critical realists believe that reliability and validity (or transferability and trustworthiness) are central to good research whatever the method (Robson 2002).

There are several ways of sourcing information for triangulation to improve trustworthiness (Denzin 1988; Yin 2003):

- *Observer triangulation*: Multiple observers report perspectives on the research topic.
- *Data triangulation*: Various sources of information are sought on the research topic.
- *Methodological triangulation*: Multiple research designs (quantitative and qualitative) are used to cover all aspects of the research topic.
- *Theory triangulation*: Different theories are used in the research design.

Triangulating from multiple sources of evidence can result in convergence of evidence. However, it opens up the possibilities of discovering discrepancies or disagreements which can be considered to be problematic (Robson 2002), but, equally, can inform the theory building process.

In this study, **Data triangulation** was used to improve internal validity. The main source of evidence from each of these subjects was *semi structured interviews*. The practical way of obtaining rich information was a semi structured interview. Direct observations and participant observation were not possible for those who had not sustained employment. Structured interviews would limit the exploratory nature of the research design and open ended interviews were not suited to the specificity of the research topic. Thus each case study was mainly represented by the four semi-structured interviews on a particular experience of sustained or ill sustained employment.

Inclusion and exclusion criteria for these interviewees were made primarily with the qualitative goal of making the information rich rather than for the usual quantitative purpose of homogenising the selected group as seen in Table 4.2.

Table 4.2: Data Triangulation

Subjects	Inclusion criteria	Exclusion criteria
Adults with ABI	Adults with acquired brain injury and vocational potential, who have participated in the Rehab UK supported employment programme and are successfully or unsuccessfully employed.	Those who did not participate in vocational rehabilitation at all.
Rehab UK Staff in supported employment programme	Those participating in fulfilling the direct roles of the job coach with the concerned client.	Indirect or no contact with concerned client in the role of a job coach.
Primary care giver / significant other.	The person/s most involved with him in the past and currently.	The primary carer is unable to provide information because of inadequate contact i.e. rotatory or temporary.
Co-workers of those with ABI	Works with, for or directly supervises the client.	No direct contact with client.

The semi structured interviews were designed to cover several vocationally relevant topics which were also common sequelae of ABI. The interviews explored the following areas. However if other topics came up these were explored.

- Physical ability – fatigue, coordination, accessibility, communication.
- Cognitive ability – specifically memory, initiation, insight (asks for help, autocorrects), creativity, speed, smoothness.
- Behavioural ability – specifically anger, stubbornness, submission, assertiveness, interaction (peer/family/superiors).
- Personality traits – perfectionism, egoism, optimism, honesty, responsibility, motivation.
- Temporal job profile.
- Consistency of work related performance.
- Disincentives and motivation

There was a concerted effort to remove all external hindrances during data collection. The topics outlined were not specifically outlined before an interview. However, after each interview, the researcher brought up the topics in this list which had not been covered. This did not happen very often. The choice of interview time and place was made by the interviewee in an attempt to make them comfortable. Phone interviews

were accepted for two interviewees who wanted to participate but could not travel from afar (the south of England and from France). If the interview continued beyond an hour, the choice of stopping and continuing later was offered though this was not chosen by any of the interviewees. Multiple interviews were made when circumstances changed significantly or when there was a problem with data recording. Again there was an open offer to discuss things again after each interviewee had read a copy of their transcript.

The other data source used in data triangulation was archival *case records from Rehab UK.* These detailed day to day reports from all members of staff provided demographic data, progress notes during and after the vocational programme, evaluations as well as key worker meeting reports with each individual. Archived data was studied in detail by the researcher. A list of specific issues and special areas of interest relating to the vocational process was drawn up and this was used to guide the semi-structured interview process.

In addition to semi structured interviews and Rehab UK records, *Addenbrooke's Cognitive Examination* (ACE) which is a 100-point test battery that assesses six cognitive domains was used . This was used because it was a rapid, effective bedside clinical test taking around 10-15 minutes to administer. Using the lower cut-off of 83, the ACE had a higher sensitivity (82%) and predictive value than the Mini-Mental State Examination (MMSE) for a wide range of dementia prevalence (Mathuranath, Nestor *et al.* 2000). Though designed to differentiate between Alzheimers disease and Fronto-temporal dementia, the ACE has been used clinically for ABI in Hunters Moor Regional Neurorehabilitation Centre and Janie Heppell Behavioural Unit. It has the advantage of being backwardly compatible with MMSE by providing an MMSE score within its own scores by including all MMSE components within the ACE. It was felt that establishing a baseline cognitive status in this way would help understand the person with ABI better and interpret their statements in the light of their cognitive abilities.

Theory triangulation (components from Ethnography, Grounded Theory and Framework Analysis were taken to supplement the multiple case study approach) has also been used to improve trustworthiness.

Internal validation is the process of improving the trustworthiness of research by removing threats to validity from within the research process. The commonest internal threat to validity or trustworthiness is bias. Quantitative approaches improve internal validity by excluding bias. The flexible approach, on the other hand, identifies bias and its impact on the research process and the topic. Both researcher bias and respondent bias were addressed in the research project using the following techniques:

- *Peer debriefing and support:* Sessions or communication with peer groups or individual experts in the field were used to explore researcher bias or other aspects of interpretation and analysis. Sessions were held either with supervisors and colleagues within Northumbria University, Rehab UK, Hunters Moor or the Regional British Society of Rehabilitation Medicine approximately once or twice a year to obtain feedback regarding the progress of the project. This again would help improve validity as well as produce a 'triangulatory' effect on researcher bias.
- *Respondent validation*: This is the process of returning completed transcripts of interviews to interviewees for comment or editing. This not only validates the process of recording and transcribing interviews but also provides an opportunity for further clarifications or explanations.
- *Reflexivity*: Reflexivity is a process of the researcher identifying personal issues and values operating in the area of research. The researcher explores how these would influence or conflict with his role in the project or with the subjects or interpretation of data. Researcher bias can thus be identified using reflexivity. The researcher reflects and outlines personal issues or values which would make him avoid or seek out situations in the process of selection and interviewing. An organization's mission statement can also subjected to a process of reflexivity (Ahern 1999; Robson 2002).
- *Audit trail*: A log of all research activity and reflection including the process of analysis and reporting is maintained so as to make transparent all potential bias which was not discovered in the above processes.

These approaches helped to reduce internal threats to trustworthiness (Robson 2002).

Analysis using a multi-method approach

An advantage of the multiple case study approach is its flexibility to analyse multiple "units of analysis". It was thought that a single case study would exclude the exploration of some contexts, given that these contexts covered a variety of demographic, clinical and social characteristics. The multiple case study approach was chosen as this would allow analysis of several contexts to be examined over a wider selection of cases. The multiple case study approach does not have a rigorous, specified approach to data analysis. It is agreed that an eclectic adoption of analytical methods which are most appropriate to the situation is preferable to the rigid adherence to one method (termed '*methodolatry*' or idolatry of one methodology). This eclectic approach has been called the **Multi- method design in clinical research** (Denzin and Lincoln 1994; Miller and Crabtree 2003). This design is developed during data collection (Robson 2002). A multi-method approach must not compromise consistency and coherence of the methods from which it is made. It must take into account the philosophical basis of each component and specify a cohesive framework of analysis between the components of various approaches (Holloway and Todres 2003). *Therefore the flexible multi-method approach was adopted to analyse the textual data in this multiple case study approach.* The specific methods used to analyse the multiple case studies are described below.

The concept of the 'researcher as a tool' was adopted (from Ethnography). Indeed, another related concept - Subtle realism - was acknowledged in the research design i.e. that the researcher influences the researched The advantages of my role as a practitioner-researcher (holding a job and carrying out research which was of relevance to the job) were balanced with the disadvantages in regard to practical constraints of time, but also the perception that I was a representative of the system had the potential to decrease trust and raise confidentiality issues during the interview process. There was a possibility that this dual role of the researcher as a service provider meant that he might be perceived to be 'outsider'. and this was considered during the interview process by clearly explaining the researcher's role while obtaining consent from the participants (Robson 2002).

The multiple case study approach would permit this flexibility by the use of *embedded analysis* of particular groups within the cases or within the contexts. Each case was taken as a set of four individuals described in the previous section. Some cases were based on individuals who had been able to sustain employment and others were based on those who could not sustain employment. The multiple case study approach allows analysis of data from these cases in a variety of ways as seen in Figure 4.1.

Figure 4.1: Analytic approach in multiple case studies

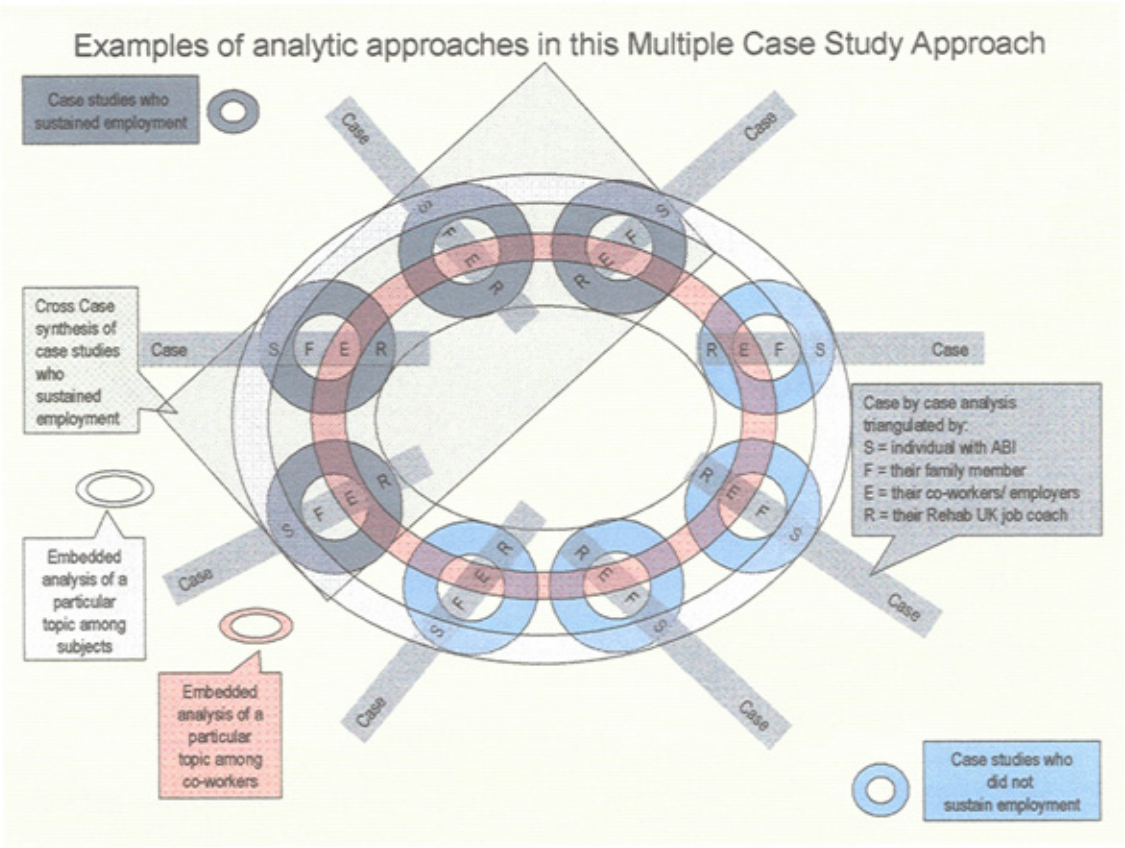


Figure 4.1 illustrates that analysis can be done in several "layers":

- Within cases: Each case could be purposively selected (described in a later section of this chapter) and based on premorbid education and work experience and each could be separately explored as a "triangulated" group (described in a later section). Each group here would consist of the individual with ABI, his relative, his co-worker and his job coach.
- Within contexts: An emerging theme could be analysed across cases using embedded analysis e.g. themes important to all the relatives could be analysed across cases using cross-case synthesis.

In addition, there are several analytical methods which can be used to analyse different "layers" of data in the multiple case study approach (Yin 2003):

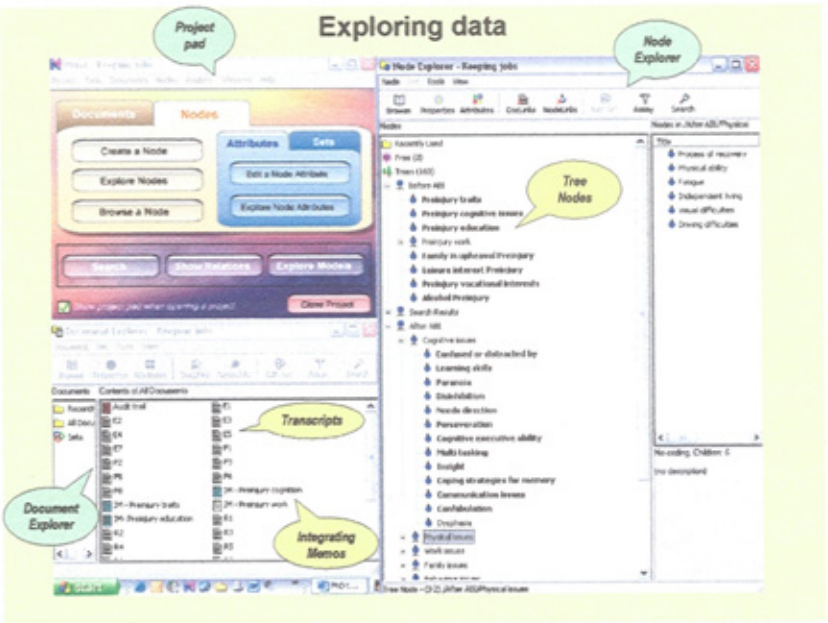
- *Pattern matching*: This method of analysis is used to explore an explanatory case study and link patterns to outcomes. Before doing pattern matching it is necessary to search the data for rival explanations or simpler explanations.
- *Explanation building*: This method is used to analyse explanatory case studies as well. It is an iterative pattern matching process. Each theory is used to revise the situation and then the revised situation is tested against the findings of the initial case, repeating the process as many times as is needed.
- *Logic models*: This method of analysis is used in case evaluations. In this analytical method, a logical process that links an event and outcome is proposed. Rival explanations, if found, means that the proposed link is either rejected as a theory or is demonstrated to be true but illogical.
- *Cross-case synthesis*: This method of analysis is specifically designed for multiple case studies. This is a concept similar to meta-analysis. The cases are subjected to individual analysis but also analysed together using the same analytical methods described above.
- *Replication logic:* This approach is common to both quantitative experiments and flexible qualitative approaches. This theory must be tested by replicating findings in a second or third neighbourhood. This is possible by choosing multiple cases and not only analysing them individually but with cross case synthesis.
- *Negative case analysis:* Negative Case Analysis is a technique described in Ethnography. This is a process of counter argument till the hypothesis is refined and accounts for all cases without exception (Robson 2002). It explores the data for contradictions in fact. It seeks to propose a rival explanation for a fact till none are found within the data (Robson 2002). It can also propose a process or a theory different from the original theory. It might discover a force larger than the project's boundaries or social trends which might provide rival explanations to the observed fact. A full exploration of these possibilities will make the process of negative case analysis improve trustworthiness in research design (Yin 2003). This method of counter argument would strengthen the case for rigour of analysis by improving validity.

The tool that was adopted to analyze the multiple case study approach was specialized 'code-based theory-builder' **software**. Software strengthens rigour of thematic analysis by the use of coding and nodes as a method of indexing, charting, mapping and interpreting themes. It is based on the iterative analytical approach of Grounded Theory. There are several commercially available software programmes – the commonest being ATLAS/ti and Non-numerical Unstructured Data Indexing Searching and Theorizing software (NUD*IST) designed by QSR International. Software programmes are mostly based on Grounded Theory principle of coding. QSR software has wide market penetration and is compatible with most operating systems and software including Microsoft Office and End Note. But most importantly, it is the one with locally available support and expertise. The latest versions of QSR software are called N6 and NVivo 2.0.

The use of software strengthens research design in several ways:

- **Improves analytical rigour** by providing a hierarchy of nodes which form thematic patterns. The hierarchy of nodes were '*a priori*' nodes which are themes which occur in the beginning usually discovered by the researcher in the first phase of data collection, '*emergent*' nodes which emerge from research subjects in the process of data collection and finally '*analytical*' nodes which emerge from patterns emerging as a result of analysis. Equally a hierarchy of analytical memos can be built – *elemental memos* which are based on specific themes, *sorting memos* which reflect on elemental memos and *integrating memos* which reflect on the relationships between other memos (Gregorio 2003). By assigning attributes or characteristics to documents or sets, it is possible to search within these sets for patterns (QSR 2002). This process of analysing these nodes and memos can be done in a hierarchical manner as well – *open coding* which is interpreting themes into a system of free nodes, *axial coding* which is linking together categories into a system of tree nodes and *selective coding* which is the selection and focus on one category that will explain and around which other categories are integrated (Robson 2002). The starting screen illustrates the possibilities of the software as seen in Figure 4. 2.

Fig 4.2: Nodes and memos in software



- **Improves transparency** in research projects through the use of date stamping the whole process of analysis and by providing **electronic audit trails** and node and document links. Even memos – the reflections of the researcher based on the nodes and the data itself – are date stamped and can be linked back to original transcripts and other related data. Therefore every stage of analysis is traceable (Bringer, Johnstone *et al.* 2004).
- **Improves reporting** of data by providing graphic modelling and reporting facilities which help show all three levels of results i.e. *theories* (an idea which defines or explains a phenomenon), *concepts* (an idea which puts a model together) and *models* (an overall framework for looking at reality). It does so by the facility of transferring node patterns to modelling figures and by generating reports including reporting some quantitative information from nodes and documents (QSR 2002).
- **Improves flexibility** by providing links to documents within and outside the project, text and other audio or graphic files, treating memos at the same level as documents (can be coded and linked) and links to other software (QSR 2002).

Thus, the use of software in data collection and analysis provides several benefits in improving reporting, rigour, transparency and flexibility.

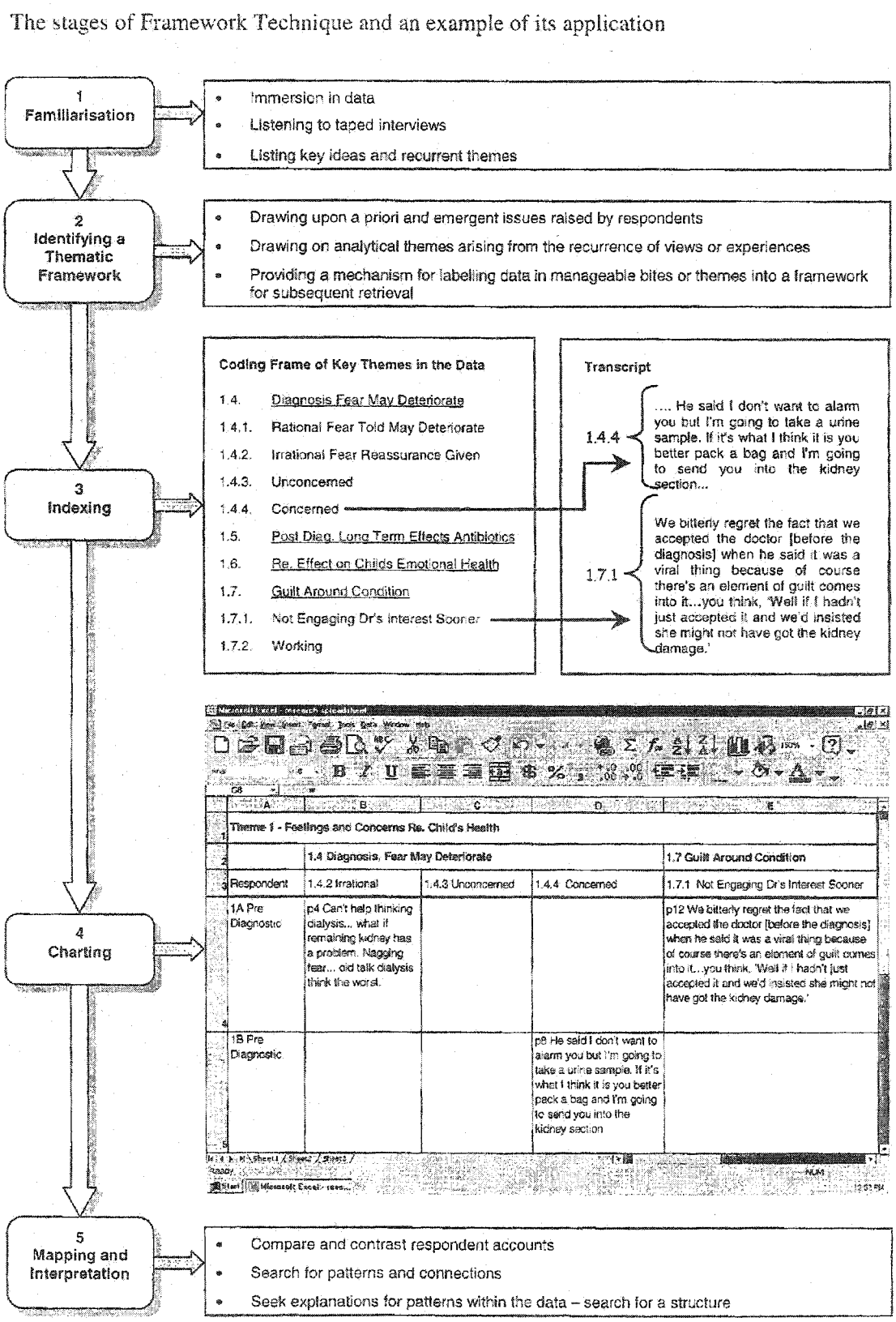
The method used to approach the analytical process in this the multiple case study was **Framework analysis**. Five stages were described as forming the Framework Analysis approach:

- Familiarization
- Identification of a thematic framework
- Indexing
- Charting
- Mapping and Interpretation.

A clear explanation of this process in presented in Figure 4.3 on the next page. These 5 stages provide a framework for analysis which improves rigour. It also provides a clear pathway to the process of analysis and improves transparency in research design (Ritchie and Spencer 1994; Ritchie, Spencer *et al.* 2003; Swallow, Newton *et al.* 2003) .

Framework Analysis provides a rigorous structural framework by using MS Excel for the stages of indexing and charting. However, these two stages will need to be more sophisticated when dealing with multiple cases. These stages are also possible using other software and the advantage of using specialized software was specifically addressed in the previous section.

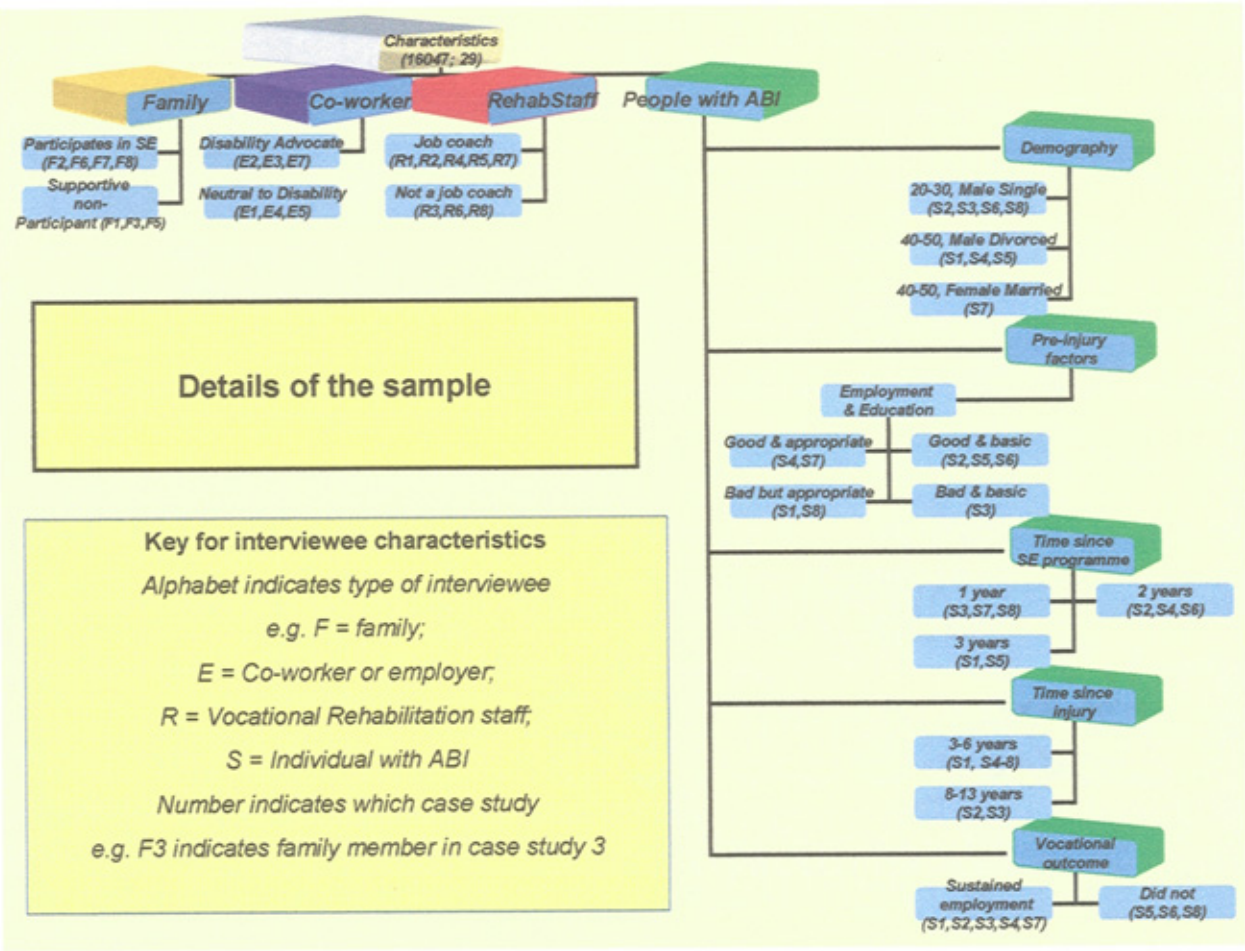
Fig 4.3: Framework Analysis (Swallow, Newton et al. 2003)



Familiarization

The 29 semi structured interviews were transcribed by the researcher himself as a process of familiarization. Transcription was done in parallel with interviewing and reflections from the transcribed data were used, along with Rehab UK's documentation to influence the general structure of the subsequent interviews. The broad topical categories emerging from the data were also identified at the end of this stage. A broad framework of interviewees' characteristics was built as seen in Figure 4.4. The green boxes indicate the general characteristics of individuals with ABI with the specific interviewees mentioned in the blue boxes e.g. S2, S3, S6 and S8 are the four male, single individuals with ABI in their twenties. An introduction to interviewees which summarizes the familiarization process is seen in the Appendix. e.g. S3 is described in Case study 3.

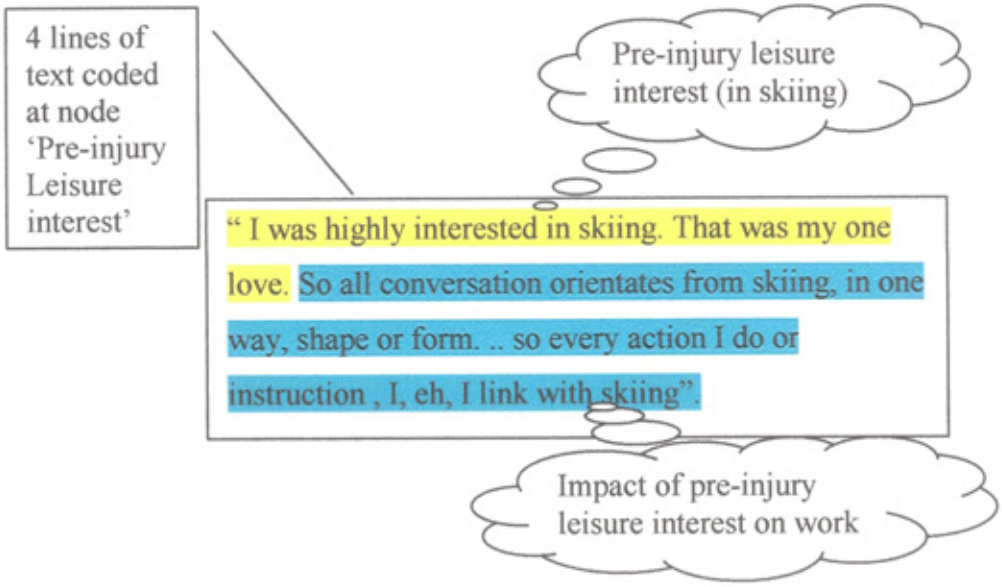
Figure 4.4: Details of the sample



Identifying themes (Open coding in Free Nodes)

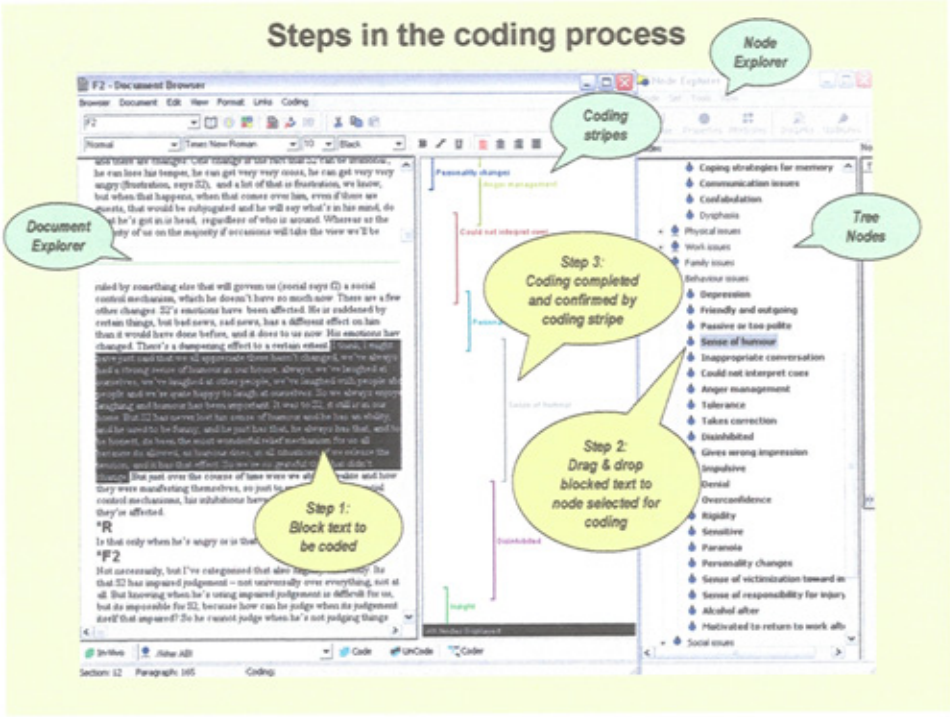
The 29 transcripts were subjected to open coding by assigning meaningful topic names to each line of transcribed text. An example of coding is shown in Figure 4.5.

Fig 4.5: Example of coding text into nodes



Coding was a three stage process as shown in Fig 4.6.

Fig 4.6 Three step Coding process



These were initially free nodes (topics coded from the data but not yet categorised). Base codes (N6) or attributes (NVivo) were assigned i.e. characteristics like demographic parameters or outcomes assigned to each document in case analysis based on these parameters were required later on.

Charting and Indexing (Axial coding in Tree Nodes)

As the picture became clearer, the free nodes were then classified and analysed by axial coding into tree nodes (categorised topics). The axial coding resulted in major topical categories emerging from the data and an example of categorisation is presented in Fig 4.7:

Fig 4.7: Tree nodes were all the topics mentioned by the interviewees about issues in ABI.

Mapping

The next step was to analyse node by node and integrate the emerging ideas using reflection, looking for rival explanations or simpler explanations and negative case analysis. There were several layers of analysis at which this analysis was done. These levels were mapped in a previous section (see Figure 4.1). The approach to analysis of

a node was based on its richness i.e. the quality of information reported by interviewees on that topic. If interviewees from all cases reported into the topic then a case by case analysis was done to identify ideas emerging in each case separately. If only some cases were richly represented in a node, then again a separate case analysis was done. Once this was done, or if the information from interviewees were scattered across the cases, then a cross case synthesis was performed, putting together all the ideas of the interviews to weave the emerging pattern of results. If necessary, embedded analysis was done across the case studies for each group (ABI individual, family member, co-worker or line manager and Job coach).

Thus each node was subjected to a linear-analytic process as described in Figure 4.1. The textual data from which this analysis was done was placed in a new set of nodes called Analytical Nodes in a transparent process. They could be traced back both to their parent node and original interview transcript. The analytical process was also reversely transparent - analytical nodes were visible in both the node and original transcript.

Interpretation

This third level of raw data was then interpreted. Each of the topics emerging under the category of issues before ABI was examined for an association between the topic and sustained employment (was it reported to help or prevent sustained employment?). If interviewees had reported it as being related, this textual proof was called as a direct association. If there was no direct association, the other variables were analysed in a cross case synthesis e.g. was the information within this topic consistent within all the cases with similar outcome, like those who sustained employment? If there was still no association, a search for a negative case analysis was done and then the node was examined for information relating to quality of work (was the topic reported to improve or harm quality of work?). If there was still no association reported by the interviewees, this data was considered as not being associated with sustained employment. This process of relating the various levels of nodes to each other was documented in memos called Integrating memos (Gregorio 2003).

Finally, directly associated topics were extracted from the data. These directly associated topics were examined for emerging themes or concepts. The emerging concepts or ideas were then woven together into a framework - a conceptual model. A thematic approach was used to build the conceptual model. Topics emerging from the data were examined for "direct association". This is defined in this study as the specific mention of a particular variable having a relationship to an outcome e.g. a family member specifically mentions friendliness as having been the reason for sustained employment. Topics could also be indirectly associated i.e. talked about but not specifically in relationship to an outcome e.g. a family member mentioning a person's friendliness but not specifying that it helped sustain employment. Only directly associated topics contributed to the conceptual model of sustaining employment after returning to work through a vocational rehabilitation programme as diagrammatically represented in Fig 4.8.

Figure 4.8: Developing the conceptual model

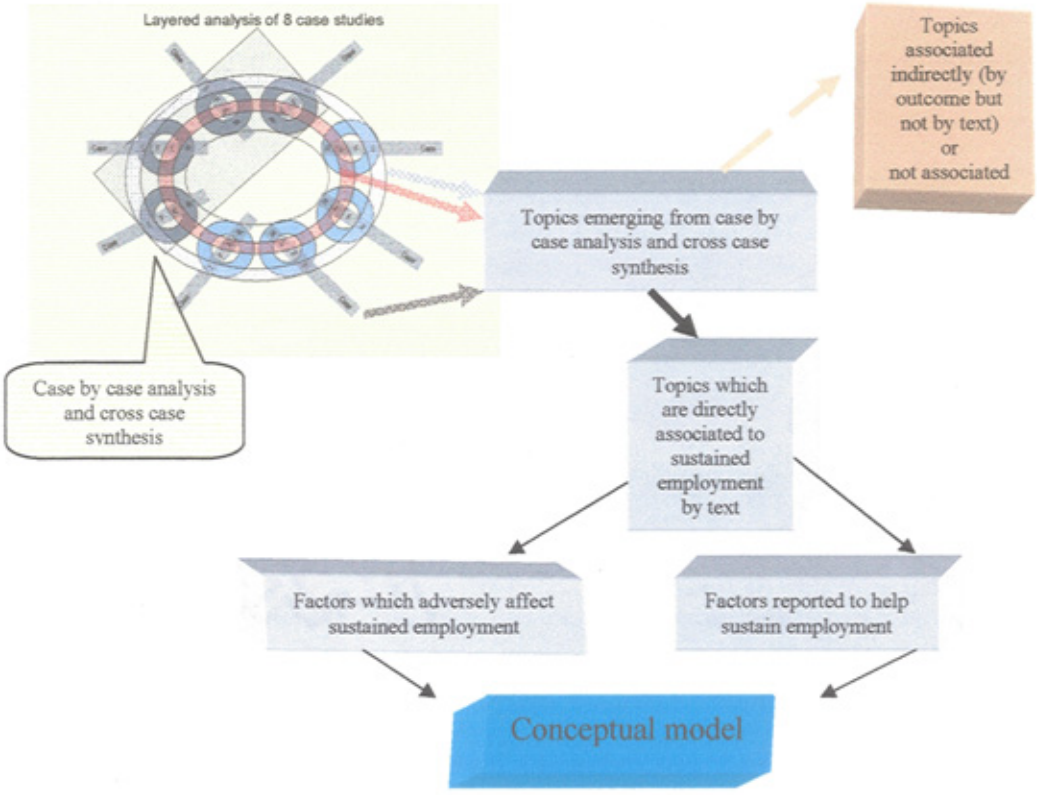
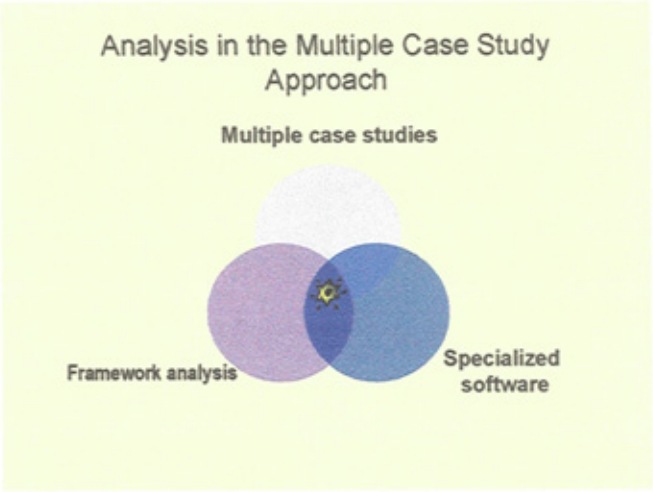


Figure 4.9 summarises the eclectic analytic approach used in this multiple case study.

Fig 4.9: Choosing a flexible and eclectic multi-method analysis: a summary



Readability

Disadvantages of the multiple case study approach are data overload and that the final document is massive and unreadable (Hamel, Dufour *et al.* 1993). This drawback can be addressed by using software which presents data in layers which are accessible through links in a user-friendly format. The analysis of each set of tree nodes is presented in the results section. The topics raised by interviewees fell into three broad categories (trees) as seen in the previous figure (Figure 4.9):

1. Issues before ABI
2. Issues after ABI
3. Issues relating to the Vocational programme

In view of the criticism that multiple case studies are massive and unreadable, a concerted effort is made to make the reporting document as concise and user friendly as possible. This has meant that full and contextual quotes are available in integrating memos in the electronic database but not in the 'Results' chapters. However references to these quotes are included as footnotes in case this needs to be examined in the database. Summaries are provided at the end of most sections and chapters. Whenever quotes are referred to or used from the data, these are indicated in the footnotes. The footnote referencing refers to NVivo data i.e. the document name and

paragraph numbers of the NVivo transcripts. The document name is based on the type of interviewee i.e.

S = individual with ABI

F = family member

R = Rehab UK job coach or key worker

E = employer, co-worker or manager.

The document number indicates the case to which the interviewee belongs e.g. F5 is the family member in Case 5. The paragraph number refers to the NVivo database paragraph number. This provides an electronic link to the actual interview as well as the nodes in which that text was placed.

The issue of confidentiality was also an issue for reporting of some parts of the analysis as this part of the research is available for public viewing. A compromise between reporting rich information and revealing identity was made and references to revealing quotes have not been reported though these are available in the integrating memos (raw data) from which they were made.

SUMMARY

Quantitative studies based on the positivist approach were unable to provide a cohesive understanding of sustained employment in ABI. A purely subjectivist approach was not compatible with current vocational rehabilitation practice. Therefore, the most appropriate research design to study sustaining employment is the flexible qualitative approach based on the critical realist philosophy which accepts the positivist (general laws are governed by quantifiable facts) hypothesis but acknowledges the subjectivist viewpoint (that these are also influenced by values).

A flexible multiple case study design was proposed as the research design to study sustaining employment after vocational rehabilitation in ABI.

Purposive selection was done in 2 stages. Maximum variety sampling was done to ensure that a heterogeneous mix of individuals with ABI was selected for the study. Then critical case sampling was done to endure that critical pre-injury issues were weighted appropriately in the final selection of multiple cases. Purposive selection was used to improve transferability and richness of the data.

Specific measures to improve trustworthiness were included in the research design like Triangulation, Respondent Validation, Peer debriefing and feedback and Audit trail.

An eclectic approach to analysis was chosen with the multi-method approach. Embedded analysis of multiple cases allowed data to be analysed in different "layers". Other basic methods of analysis including negative case analysis were used to analyze the data. NVivo software was used to make analysis transparent and manageable. The structured process of Framework Analysis was used to carry out the analysis.

Thus the flexible qualitative multiple case study design was used and 8 cases were purposively selected. Each case composed of an individual with ABI, his family member, his co-worker and his job coach. Semi structured interviews of these 32 subjects were planned. Twenty nine semi structured interviews were completed for eight case studies. Issues emerging from these interviews were identified and categorised into tree nodes. Each tree node was analysed in layers both case by case as well as contextually with embedded analysis, cross case synthesis or negative case analysis. Ideas directly associated by textual data were built up to develop concepts. Concepts were then used in the development of the conceptual model. This was reported in a form that was concise and anonymous.

CHAPTER 5

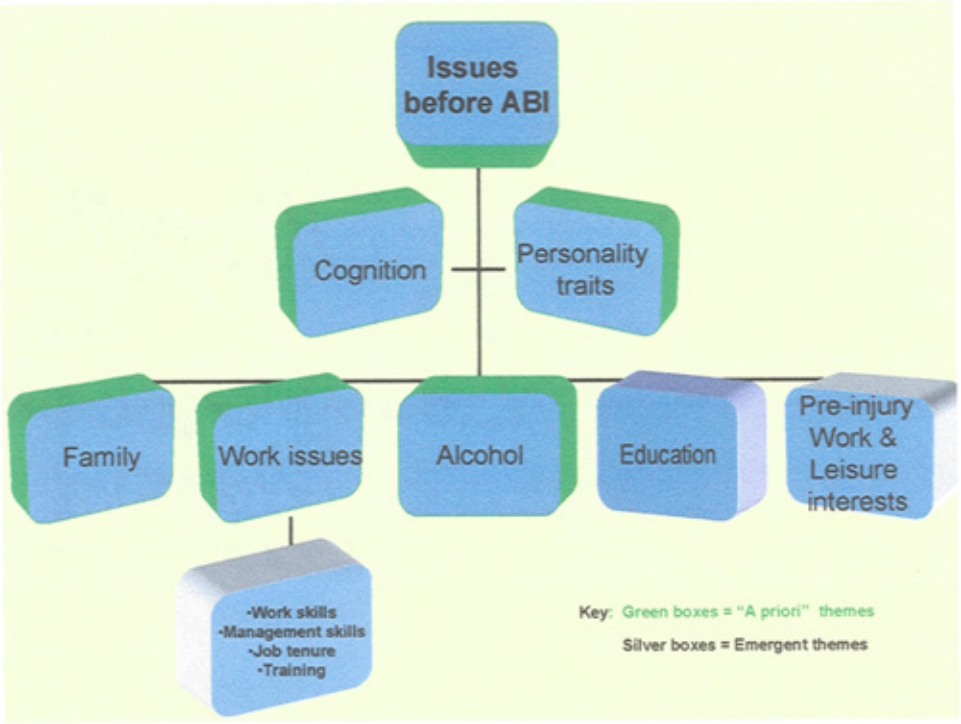
PRE-INJURY FACTORS

This chapter analyses the pre-injury issues raised by interviewees. The first section relates to pre-injury topics which were directly linked by text to sustaining employment and the next section to those not directly linked by text, but associated with outcome.

PRE-INJURY ISSUES DIRECTLY ASSOCIATED WITH SUSTAINING EMPLOYMENT

Pre-injury issues which were directly associated by text with sustained employment are presented first. Topics relating to issues before ABI were coded into 'a priori' nodes (topics relating to ideas at the beginning of the coding process) and 'emergent' nodes (topics relating to ideas emerging while coding). These nodes are outlined in Figure 5.1.

Fig 5.1 A priori and Emergent nodes about Pre-injury issues



A priori and emergent nodes were analysed node by node using both individual and cross case synthesis approaches.

Whenever quotes are referred to or used from the data, these are indicated in the footnotes. The footnote referencing refers to NVivo data i.e. the document name and paragraph numbers of the NVivo transcripts. The document name is based on the type of interviewee i.e.

S = individual with ABI

F = family member

R = Rehab UK job coach or key worker

E = employer, co-worker or manager.

The number indicates the case to which the interviewee belongs e.g. F5 is the family member in Case 5.

The impact of leisure interests in sustaining employment[1]

There were several leisure interests (gardening, mountain biking, partying and sports) recorded in the data but two were specifically associated positively with sustained employment e.g. S4 enjoyed interacting with little children and said "*God knows I love to play with kids and make them happy. Anything to have kids happy and laughing is more important thing to me than anything else*" and said his "*life revolved around*" his own children when they were small [2].

Though S4 had a good job placement which successfully resulted in a job offer at the end of the placement period, S4 did not pursue this. Surprisingly he then lost formal contact with the programme and proceeded to attempt several jobs on his own. But the breakthrough was a voluntary job making meals for homeless children. He had finally found a job of which he said "*75 pence an hour. But it wasn't the money really, was taking out of the house, do something I really enjoyed, see the kids happy (laughs).*" He'd do anything for them and loved the interaction and this was the first job he sustained for a prolonged period of time, stopping only because he needed gall bladder surgery [3]. Indeed this job marked the beginning of S4's improved ability to sustain employment [4].

Another example was S2 whose leisure interest was skiing. His father said of S2 that "He had no skills other than ski skills" [5]. S2 himself said that too: "*I was highly interested in skiing. That was my one love. So all conversation orientates from skiing, in one way, shape or form. .. so every action I do or instruction , I, eh, I link with skiing*" [6].

S2 had had several unsuccessful placements more out of a lack of his interest rather than an inability. Again the turning point was a winter job which happened to fall in place after a holiday. This has resulted in sustained employment every winter - not

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[1] Integrated memo: IM – Pre injury Leisure interest
[2] Document 'S4', Paragraphs 143-146, 192-193.
[3] Document 'S4', Paragraphs 377-381
[4] Document 'S4', Paragraphs 369-373, 396-401
[5] Document 'F2', Paragraphs 79-81
[6] Document 'S2', Paragraphs 23-28

only in his cleaning job at a ski resort but also in helping teach children to ski there. His employer said of him, "*we've used S2 occasionally for lessons. And that's the direction particularly he quite likes. So we've actually tried to have him less on the cleaning side of things and more into the instruction side of things. He likes doing that and the situation allows us to do that at the moment, but not every week. That's one week in three he'll be doing some instruction. But I think he likes doing, he enjoys doing that. Especially when the kids are responsive, and generally they are, with him*"[1].

Thus, in the study, the interests that individuals hold outside their working lives often remain intact after the brain injury and were directly associated with sustained employment.

The impact of pre-injury work interests on sustaining employment[2]

Data reveals that S1, S4 and S5 liked their previous jobs for a variety of reasons.

S1 felt his work in quality control over 20 years gave him job satisfaction [3]. S4 felt that his job as a waiter for 8 years and his involvement in restaurants and pubs for around 11 years was something he had been happy with – "*couldn't complain*" [4]. S5's daughter felt that he always had a sense of pride in his work [5].

All of them gravitated to jobs around their previous work interests.
S1 began with a data entry placement, which he converted to a job and at the first opportunity got a promotion to a quality control role in the project within the same company [6].

S4 gravitated to a placement around catering as the vocational programme had recognized this interest [7]. He eventually got a voluntary job on his own after he lost

[1] Document 'E2', Paragraphs 313-321
[2] Integrated Memo: IM – Pre injury work
[3] Document 'S1' Paragraphs 69-77.
[4] Document 'S4', Paragraphs 92, 107, 280-287.
[5] Document 'F5', Paragraph 15
[6] Document 'S1' Paragraphs 273-279
[7] Document 'R4', Paragraphs 213-214.

contact with Rehab UK and has remained in the catering business after returning to paid employment [1].

S5 says he keeps trying to get back to his work as a garage manager [2]. When he realized this was impossible, he said "*I've lost me job, lost me company car, lost me ..., lost me house cos I've had to sell that since the divorce, and ... I've lost everything really*". He was very despondent and indeed has not returned to paid work [3].

Though the younger people had no pre-injury paid employment, there is a similar driving force of previous work interest.

S3 did not have pre-injury paid employment but was very involved in computers at home before the injury [4]. He too said it was good to get back to computers when he returned to work [5]and this was echoed by his manager who knew S3 was very interested in computers, and tried to "*give him extra work on computers*" [6].

S8 did not have a particular pre-injury vocational interest or employment but after he moved out of his first placement-turned-job as a waiter and with his degree in leisure and tourism, he is looking for another job as a waiter [7].

S2 was from a family who had a ski business and apart from it being his leisure interest as mentioned before, it was also the family business and his employer said, "*S2's family were involved in the skiing business. He was brought up with it. I think that's what – he's always felt it was a part of him. Being involved in the skiing industry. Because of his background really*" [8]. So it was also a previous work interest and was associated with sustained employment after his return to work.

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[1] Document 'R4', Paragraphs 270-273.
[2] Document 'S5' Paragraphs 631-633.
[3] Document 'S5', Paragraphs 678-681.
[4] Document 'S3', Paragraph 21
5 Document 'S3', Paragraph 101
6 Document 'E3', Paragraphs 182-183
7 Document 'S8', Paragraphs 584-590
[8] Document 'E2', Paragraphs 13-16

S6 worked in the Territorial Army and was "*very addicted to the army*" which unfortunately did not work out for reasons unrelated to the traumatic brain injury - he had metal implants for leg fractures which occurred during the accident. However he had "*no difficulty*" working part-time in the Territorial Army despite not being able to sustain his other paid employment [1].

Thus, irrespective of age, all subjects seemed to sustain employment which was similar to their pre-injury work interests or skill. Every person with previous work interests eventually tried to go back to their original area of work or interest (no negative case analysis in the data). Even S7, who did not particularly express a like for the administrative job that she used to do, also converted a similar placement to paid employment and has sustained employment successfully [2].

Thus, in this study it appears that previous job familiarity and interest are directly associated with sustaining employment. In fact the data shows that people prefer to return to the sort of job they were used to even if it is not appropriate to their post injury ability.

The impact of pre-injury work skills on sustaining employment [3]

Previous work skills had a direct positive impact on S1 and S2's sustained employment. S1's job coach reported that "*S1 was coming in with a range of skills that no one else in the placement had and he very much made a job for himself*" [4]. S2 also had previous skiing skills [5] which were recognized and used by his employer and therefore helped in sustaining employment.

In S4's case, his previous work skills and practice were retained and were good but unfortunately came into conflict with practice at one of his work places and resulted in poorly sustained employment when combined with the inflexibility [6]. This poorly

[1] Document 'S6', Paragraphs 315-316, 653
[2] Document 'R7', Paragraphs 159-164
[3] IM – Pre injury work
[4] Document '1R', Paragraphs 193-195
[5] Document '2S', Paragraphs 33-35
[6] Document '4S', Paragraphs 523-527

sustained employment could be attributed to a combination of a poor working environment and inflexibility. However his previous skill with handling difficult customers did come in handy in subsequent employment. This was demonstrated in his handling of one particularly difficult situation: "*They were drinking till 5 o'clock in the morning. I don't mind. The bar supposed to be closed. Jack tells me when I close the bar they had a lovely day, they had a lot to drink could not make any noise, they don't fight, they're not arguing. They're just talking . I stopped the bar at 1 o' clock, they start arguing because they want more drink. When they had so much to drink, what they want is more. So you give more, they fall asleep and they're happy, they go to bed and let them* [1] *... And Gill says, "How did you manage that?" I says, "I don't know" (we laugh)*" [2].

Previous work skills were associated with sustained employment in S1, S2 and S4. S5 lost his previous skill and could not sustain employment .

Even though there is descriptive data available on the pre-injury work skills of S6 and S7's work, there is no direct link reported by the interviewees from this to sustaining employment later [3]. There is no mention of S3 and S8 as their injuries occurred before their paid working lives started. Even other training skills mentioned in the interviews such as IT skills and army training were neither linked nor associated with sustained employment [4].

Thus, there were 3 cases directly linking retained pre-injury work skills with sustaining employment (S1, S2 and S4) and one case where the loss of skills resulted in poorly sustained employment (S5).

[1] Document '4S', Paragraphs 627-634
[2] Document '4S', Paragraphs 642-643
[3] Tree node: pre injury work skills
[4] Tree node: Pre injury training

The impact of pre-injury personality on sustaining employment[1]

There are several examples of pre-injury personality characteristics which had an impact on the individual's ability to sustain employment later.

The first example was the individual with ABI in Case 5 (S5). Before his ABI, though he had an argumentative personality, his co-worker said, "*When he thinks its wrong, he would say it was wrong and devil with the consequences, you know. And sometimes devil the people who were standing around him when he started voicing them*" [2]. "*He was the type of person who would shout at somebody and then feel guilty about it afterwards and then go make up with him and then be best buddies*".[3] Because he would easily make up after a disagreement, his co-workers referred to him as being like their father or their mate.[4] However, after the ABI his co-worker reported that he could no longer make up afterwards with "*boyish banter*" [5] and his inability to maintain relationships with his co-workers was mourned. He said about S5, "*I felt that we'd lost that. You know. It was gone*". [6] This was one of the reasons why he was not able to sustain employment in his previous work place. Thus, we see that not being able to make up for a short temper adversely affects sustaining employment.

Similarly S5 was also a very impulsive person before the ABI. He would state his opinion impulsively irrespective of the consequences (see above) but he was "good at organising the shop floor" and even though "*some of the lads used to duck and run away*" if he lost his temper, "*this was tolerated because he was good at his job*".[7] After the ABI, his impulsiveness was, sadly, not compensated by his work efficiency. Without this balance of efficiency, S5's impulsiveness was no longer accepted and he was removed from the job to which he had returned.[1]

S5 also bypassed established lines of management. E5 (S5's immediate junior who took over) felt that even before his stroke, S5 would ignore management protocol – he

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[1] Integrated memo: IM – Pre injury traits
[2] Document E5, Paragraphs 457-472
[3] Document 'E5', Paragraphs 127-140
[4] Document 'E5', Paragraphs 37-42
[5] Document 'E5', Paragraphs 333-340
[6] Document 'E5', Paragraphs 333-340
7 Document E5, Paragraphs 457-472, Paragraphs 151-160

talked about how he could not bring himself to initiate disciplinary proceedings as a manager even though he was willing to shout at workers for their inefficiencies.[2] This certainly became more pronounced afterwards. F5 (S5's daughter who was a bank manager) described him as bypassing all standard bank procedures to demand an ex gratia payment of around £10 for the loss of 0.33 pence as a result of a standing order not going on a weekend.[3] S5 himself admitted that after the ABI he had bypassed standard complaint procedures in his company and complained to the general manager about a supervisor. [4] But when he talked about this experience he did not recognize this as an adverse trait affecting his ability to sustain a job. He said, "*So in retrospect, I was kind of pleased because on one hand, because I was right in the first place*".[5] Neither was his job coach able to modify this behaviour. She felt that he had a lot of family problems and that this affected his ability to cope. [6] However there is no indication that there was knowledge that this was indeed a pre-injury trait which was magnified afterwards, rather than something new appearing post-injury. This understanding came from his co-worker who knew him well.

Thus there is evidence in the data that personality traits described as adverse can adversely affect sustaining employment – specifically highlighting anger management and bypassing established lines of management.

Equally there is evidence that previous friendliness continuing later helped to sustain employment.

S2's parents said that S2 "*had always been helpful, his nature's been very gentle and kind, thoughtful, he'll help anybody, he's always been like that*" [7]. This redeeming trait persisted post brain injury and they felt that he hadn't changed and was still polite and friendly with guests at work [8]. This was corroborated by his job coach and by his employer who said that he was very popular at work because of his friendliness and

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[1] Document E5, Paragraphs 273-284.
[2] Document 'E5', Paragraphs 127-140.
[3] Document 'F5', Paragraphs 199-206.
[4] Document 'S5'Paragraphs 277-286
[5] Document 'S5', Paragraphs 286-288.
[6] Document 'R5', Paragraphs 321-326
[7] Document 'F2', Paragraphs 33-35
[8] Document 'F2', Paragraphs 100-105, Paragraphs 149-150.

that his popularity was an asset to the business [1] [2]. And, indeed, the best compliment of all from a satisfied customer who reported later to his parents, "*I had the best day I've ever had with S2*". And that was from a person whose first impression of S2 was that he was drunk. [3]

Another of S2's pre-injury traits was his dependability. He could be depended on to run the family business when his parents were on holiday [4]. This characteristic was described by his post-injury employer as one of his best assets [5].

Therefore in this study there is evidence that good pre-injury personality traits affected sustaining employment positively.

On searching for rival explanations or data with contrary evidence (negative case analysis), an interesting example was noted: Though adverse pre-injury personality traits are detrimental, there is evidence to show that, when recognised and modified by the person with ABI and SE staff, this can be corrected in such a way as to sustain a job and indeed be promoted.

This was the case with S1. F1 (S1's father) said that before the ABI, S1, as a young man, was forthright enough to challenge police in another country and go to jail for his convictions [6]. S1 himself reported an instance of leaving a job when he felt his job was undermined because his employer no longer wanted to maintain standards of quality [7]. This element of intolerance was recognised by vocational rehabilitation staff who said, "*Because that was certainly the case with the lads on the programme. If he felt they were not committed, and they were not working as hard as they should, he got quite intolerant*". In fact it was felt that it might affect work [8]. S1 was encouraged by the Rehab UK staff to discuss things with his key-worker [9]. When he returned to

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[1] Document 'R2', Paragraphs 23-24.
[2] Document 'E2', Paragraphs 65-68, 72-78, 322-327
[3] Document 'F2', Paragraphs 282-284
[4] Document F2, Paragraphs 48-50
[5] Document E2, Paragraphs 323-327
[6] Document 'F1', Paragraphs 39-46
[7] Document 'S1', Paragraphs 10-21
[8] Document 'R1', Paragraphs 253-259
[9] Document 'R1', Paragraphs 113-119

work, S1 himself recognized this and continued to take counsel from his key-worker, who also visited him at work and helped him cope [1].

Interestingly this was considered a post-injury trait rather than an exacerbation of a pre-injury trait. Eventually when S1 acted, he did so wisely and managed to get a promotion by taking the help of one of the directors of his company [2]. Though this situation was as bad as his pre-injury work situation, his response and the outcome were much more positive than even the pre-injury situation!

Therefore, in this study personality traits described as adverse were actively recognised and dealt with both by the person and SE staff and this was demonstrated to modify these traits.

Another negative case analysis was an example of a pre-injury trait described as good which became an obstacle to sustained employment.

S4 loved a friendly workplace and during pre-injury employment, he took great trouble to make sure his co-workers and employees were happy. He said, (English is not his first language), "*One good thing is that I'm most of all a people person. I'm friend to everyone, I do my work. I go out of my way to help anyone – old, young, I've dropped everything to help, doesn't matter who it is. I'm there jump in*" [3].

However, his employer described this as being disruptive when things got busy at his work place. She said, "*when I first met him, he was more like a hyper child, always wanting, you know, and wanting to prove*" [4]. Fortunately, S4 was able to recognize and correct this – he was able to prioritize and recognize when to help constructively[5]. So this pre-injury personality trait did not affect his sustained employment.

Apart from the fact that traits described as adverse can be modified and that traits described as good can affect employment adversely, there are no other negative case

[1] Document 'S1', Paragraphs 213-220
[2] Document 'S1', Paragraphs 273-279
[3] Document 'S4', Paragraphs 119-122
[4] Document 'E4', Paragraphs 217-231
[5] Document 'E4', Paragraphs 217-231

analyses within the data. Though data shows that personality traits can be modified, there is no data which reveals pre injury traits changing for the better spontaneously. There was some inconsequential evidence in that S3, S4, S7 and S8 showed triangulated evidence of unchanged personality traits which were not demonstrably linked to sustaining employment.

Thus, work related pre-injury traits remain unchanged or magnify post injury. While traits described as good helped sustain employment and vice versa, this could not be automatically assumed. If the effect of these traits were recognised and addressed by the person with ABI and by staff, data showed that they helped sustain employment and indeed, an attempt to modulate traits was demonstrated, not only to result in sustained employment, but also in job promotions.

All the above pre-injury topics were reported to have direct impact on sustained employment. The next set of topics do not report direct links with sustained employment but do indicate associations with it i.e. topics are associated with the outcome of either sustained or poorly sustained employment.

ISSUES NOT DIRECTLY ASSOCIATED WITH SUSTAINED EMPLOYMENT

Pre-Injury Management Skills

Only S1, S4, S5 and S7 had successfully performed managerial roles before the ABI. S1 worked in quality control systems management in the past [1].

S1 was promoted to a manager's role around a year after returning to work. One indication is his management style which was simple and almost mathematical. He said, "*It was purely governed by system.. if something wasn't acceptable, it was put on hold or was rejected. Simple. .. there was no emotion whatsoever from my point of*

[1] Document 'S1', Paragraphs 57-60

view. I'd set rules that I'd established. British standard, the ICI standards. I got that for them. That's why I was taken on" [1].

In contrast, S5, had been a successful manager before and never had anyone leave from his team before the ABI [2] – his co-worker described it as a "winning team" [3]. But S5's management style was more fiery and demanding as his co-worker described him: "*But he liked everything like bang, bang, bang. Everything had to be just so done. Which is how it should be I suppose*" [4]. But, as mentioned in the personality issues study of Case 5, the compensatory approaches that he used in combination with this fiery managerial approach were missing and he was not able to perform this role later and could not sustain employment.

S4 had successfully run several teams of staff and stock before his injury [5]. S4's managerial skill was characterised by being flexible with his staff [6]. However he did not require managerial roles on return to work and so it was not possible to explore the effect of his pre-injury managerial skills on his ability to sustain employment.

S7 had a very minimal managerial role (managing rotas for domestic staff). Her managerial style was not described in the data. She did not require managerial skills when she returned to work.

Thus, if a managerial role was required on return to work, previous positive managerial styles were associated with individuals who sustained employment and vice versa. However there were no direct textual links between the managerial styles and sustaining employment.

[1] Document 'S1', Paragraphs 44-47
[2] Document 'S5', Paragraphs 479-482
[3] Document 'E5', Paragraphs 90-91
[4] Document 'E5', Paragraphs 42-43
[5] Document 'R4', Paragraphs 75-81
[6] Document 'S4', Paragraphs 269-270

Pre-Injury Job Tenure [1]

Most individuals who had worked before the ABI came within the average general sustainability of at least around 5-10 years of working with the same employer. S1 had around five years before he lost his job just before the sub-arachnoid haemorrhage. S4 had worked for around 4 years in a hotel before becoming a publican around a year before his assault. S5 had worked for around 12 years in the same company and S7 around five years at her company at the time of their strokes. S2 and S6 had working lives of around four years only at the times of their accidents. S2 had worked with his parents' business from the age of 14 till his accident at the age of 18. S6's third job alongside his father as a specialist construction worker, had been ongoing for a little under 2 years.

Table 5.1: Pre-injury Job tenure

Pre-injury Job Tenure	S1	S2, S6	S4	S5	S7
In number of years	5	4	12	5	4

The others (S3 and S8) had not yet started employment at the time of their accidents. Thus those who worked before had reasonably stable jobs [2]. There is no data indicating that pre-injury job tenure was a factor affecting sustained employment.

However an association between a work culture of expecting to "move on" was noted by S4 in pre-injury employment – he said "*If there was one section decide, the head chef or head waiter will go on strike, we don't work. Every other section was prepared to take over that – every single to do anything in the hotel, doesn't matter what it is , everyone was prepared to* ***move on****. If something happened there, say we don't work till we get more wages or things like that*" [3].

[1] Integrated memo: IM – Pre injury work
[2] Analytical node: AN Job tenure pre injury
[3] Document 'S4', Paragraphs 65-70.

S4 did not feel the need to sustain employment unless he liked the job (his first language is not English) as he said, "*Sometime its scaring to work on the job I'm doing. I'm there not because I have to.. cos I like to. . It's a different thing*" [1].

So, though there is no direct link in the data, perceptions of "moving on" are associated with a different perception of sustained employment.

Pre-Injury Cognitive Function [2]

Only S6 had a premorbid dyslexia. Until this was recognized his IT trainer in the SE programme reported difficulty in stage 1. He could not understand some of the questions which were on the written task sheets [3]. Despite this, S6 had ongoing difficulty with sustaining employment as he had a shift job with a written rota and no modifications. His inability to read the rota meant that he occasionally missed shifts [4]. However there was **no data** to show that this directly caused poor sustenance of employment. Pre-injury cognitive ability was not an issue raised in any other case study.

Pre-Injury Education [5]

All people with ABI in the study had been to school and done GVQs but no further. This is a definite bias in the data for a lower level of education. However even at this less-than-college level of pre-injury education, there was **no evidence** to support previous research that education, however appropriate, had an impact on sustaining employment. This is a particularly interesting finding as pre-injury education was one of the criteria of purposive selection.

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[1] Document 'S4', Paragraphs 828-830.
[2] Tree node: Pre injury Cognition
[3] Document 'R6' Paragraphs 11-16.
[4] Document 'S6' Paragraphs 665-667.
[5] Tree node: Pre injury education

Pre-Injury Family Support [1]

Family had played an important role in all but S1's life. He was separated at the time of injury and having to leave home was reported by his father as a tremendous setback. "*Things went from bad to worse and he turned to the bottle*" when he had his sub-arachnoid haemorrhage [2]. However there was no evidence in the data to show that this had any direct impact on sustained employment.

On the other hand, there was a critical example of S8, who directly attributed his post-injury will power to the memory of his role model grandfather. He said, "*My granddad, my mum's dad – he died, and he was a really strong man, the strongest man I've – like a role model for me. And when I couldn't walk, and I was on the exercise bikes in Hunters Moor, I used to hear him say, Come on, Keep going, Keep going*"[3] . S8 felt he was an inspiration and had helped his achievements [4].

Thus, there is no direct evidence to show that pre-injury family characteristics are associated with sustained employment. However the data reveals that there are **positive benefits of an inspiring role model in motivation to rehabilitation.**

Pre-Injury Alcohol [5]

Most vocational programmes do not readily accept people with previous problems with alcoholism. Though the use of alcohol is mentioned pre-injury, there are no reported problems with alcohol pre-injury and there is a paucity of data regarding the impact of pre-injury alcohol problems on sustained employment.

However there is one exception in that S1 had failed to solve his pre-injury alcohol problems, despite a failed attempt by his pre-injury employers at detoxification programmes. Though he had successfully stayed off alcohol for a year after the detoxification programme, he had returned to alcohol after that. He had lost 2 jobs as

[1] Analytical node: AN Family Pre injury
[2] Document 'F1', Paragraphs 23-25.
[3] Document 'S8', Paragraphs 548-552
[4] Document 'S8', Paragraphs 565-569
[5] Integrated memo: IM – Pre injury alcohol

a result and was unemployed at the time of the brain haemorrhage [1]. However, he was accepted by Rehab UK. He was teetotal post injury and this has not been an issue afterwards [2].

SUMMARY OF ISSUES BEFORE ABI

1. Previous Job Interests were also reported as a strong motivator to both seeking and sustaining employment. Without exception, all cases sought an area of previous work experience or interest, and those who found it sustained employment. One case where such a match was not possible, could not sustain employment even after vocational rehabilitation.

2. Previous Leisure interests were discovered and used by people with ABI (rather than being discovered by vocational rehabilitation services) to seek and sustain employment. This is another strong association of pre-injury factors in sustaining employment.

3. Pre-injury Personality traits have been reported as having direct impact on sustaining employment by several interviewees.
    a. Generally, traits described as good (friendliness) helped and traits described as adverse (impulsiveness, anger management, by-passing established lines of management) did not.
    b. There was one case where being too helpful came in the way of work (but this did not affect sustaining employment).
    c. If traits described as adverse were recognized and modified, this was good for sustaining employment and the case showed an excellent result of promotion as well.

4. Previous positive work skills were associated with sustaining employment and vice versa.

[1] Tree node: Alcohol pre injury
[2] Tree node: Alcohol after

5. Previous positive managerial styles were indirectly associated with sustaining employment and vice versa.

6. Pre-injury cognitive, education and other training skills were not reported to be associated (directly or indirectly) with sustained employment.

7. Though family support was not directly related to sustained employment, the importance of a family member as a positive role model in the general rehabilitation process was reported.

8. Though pre-injury job tenure (length of employment) was not directly associated with sustained employment, a report of a previous job culture of "moving on" (short job tenures) was noticed in conjunction with a different perception of sustaining employment.

9. Pre-injury alcohol issues were not reported to be present in all cases but one and that person was teetotal post-injury.

CHAPTER 6

POST INJURY FACTORS

This chapter analyses the results of the a priori and emergent nodes of the various topics around issues after ABI. The Post-injury factors were related to factors impacting sustained employment in individuals with ABI (Cognitive, Psychiatric, Behavioural and Physical issues) and those relating to their environment (Family, Social, Financial and Work related issues). Footnote references to interview transcripts and nodes and memos in the NVivo database are used as in the same format as the previous chapter.

THE IMPACT OF BEHAVIOUR AND PERSONALITY AFTER ABI ON SUSTAINED EMPLOYMENT [1]

The fact that personality had changed after ABI was reported by several interviewees.

For some parents they could see their teenager again: "*We got S1 back again... we get about 30 years of a different S1 .... Then we got him back as he was - very interesting*"[2].

For others, ABI resulted in exaggeration of previous personality traits: "*If he had a strength in one direction, or a weakness in that direction, then that could well be exaggerated after his accident. And that has happened. So the fact that S2 was laid back before his accident, so now, he, in terms of ambition, he's even more laid back*"[3]. S7 said, "*I used to* (have a) *temper before I had my stroke anyway, but not as much as I did go for the last two years*" [4].

Other co-workers and family mourned the loss of the previous personality [5]. Others reported that the personality change had meant that the person no longer had friends as before [6].

The impacts of these changes are discussed below. A majority of the behavioural factors and personality traits present after ABI that were described had an impact on work quality, but only four of those affected sustained employment. These four are described in detail.

Impact of a friendly outgoing personality on sustained employment

S1 was a friendly person and he specifically cited his patience as helping him at work when training workers in another country with a different culture [1]. He got along well

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[1] Analytical node: AN Behaviour~Personality after
[2] Document '1F', Paragraphs 365-367.
[3] Document '2F', Paragraphs 710-713.
[4] Document '7SF', Paragraphs 605-624.
[5] Document '5F', Paragraphs 235-236, 239; Document 'E5', Paragraphs 602-603.
[6] Document 'F6', Paragraphs 335-338.

with his co-workers who complimented his graciousness: "*From day one, I got on with S1 very, very well and never really had any hassle with him. He's probably the only man I've ever worked with that I haven't had an argument with or any hassle cause he, hey, I don't think I possible could, cause he's too much of a nice bloke to do it, you know*" [2].

S2's friendliness was an asset for his winter job and he was complimented by his employer for this: "*From a business point of view, I think, most of our clients are highly appreciative of him being there. They like his company*" [3]. It was the same for his summer job as well: "*What he does is he goes around quite a lot of elderly people, chases them up, cuts their grass, has a cup of coffee with them, makes their morning, that everybody is benefiting from that*" [4].

It was the same for S3 - he was complimented by his employer for his friendliness which helped him make customers feel happy: "*I'd say the best thing, which is always consistent in him, has been his customer care ability. He's always chatty, always willing to help, spend time with the customer, make sure they go away happy which is always a good thing, and easier*" [5].

S4 was also friendly but there was no data associating this trait with sustained employment though there were instances where his friendliness was highly complimented at work as a gentleman [6].

There were no specific comments for the others though S7 and S8 got along well with everyone at work.

However, S5 had several problems with interpersonal relationships which have been described in detail in the section on pre-injury traits. Interestingly he had no problems

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[1] Document 'S1', Paragraphs 650-653.
[2] Document '1E', Paragraphs 183-187.
[3] Document '2E', Paragraphs 77-78.
[4] Document '2F', Paragraphs 776-778.
[5] Document '3E', Paragraphs 224-227.
[6] Document '4R', Paragraphs 58-60, Document '4S', Paragraphs 823-825.

when he did a placement in a different company than his own [1] (This was not pursued as the plan was for him to return to his own company).

Thus friendliness has helped sustain employment in three cases as well as improved work quality in two cases.

Impact of motivation on sustained employment

S1's ability to return to work and keep his job after going through several difficulties was attributed to his motivation: "*I think S1's quality that really got him through was his motivation and dedication. Here was a man who was absolutely determined to get his life back on track. Because in addition to the work side of things, family side of things fell through as well, which is very, very common. He had a difficult break up with his wife but was determined to get through that, get his life on track, get himself a new house .. relocate .. he showed unwavering motivation and determination and that is easily his greatest quality*" [2]. His parents said that he felt that if "*its happened, nothing you can do about it, get on with it*" [3]. He said his main motivation to do so was to prove a point to himself [4].

S2 was also a highly motivated young man who sustained employment and his parents said, "*He wants to be independent, and he wants to prove that he's independent, therefore he's going to do that, come hell or high water*" [5].
There was no mention of S3's own motivation though he did have a sense of victimization [6], he had overcome it and felt that " *now there's nothing I can do, just get, put my head down and keep going*" [7].

S4 felt that he did not have to work, but that he would like to work.
He was motivated to do so by wishing to prove a point that "*he's as good as if not better than he was before his accident*" [1]. This motivation was not mentioned in a

[1] Document '5R', Paragraphs 146-148.
[2] Document '1R', Paragraphs 239-246.
[3] Document '1S', Paragraph 409.
[4] Document '1S', Paragraphs 195-198.
[5] Document '2F', Paragraphs 521-523.
[6] Document '3S', Paragraphs 449-450.
[7] Document '3S', Paragraphs 454-455.

positive way as his manager described him as being "*like a hyper child, always wanting, you know, and wanting to prove. I should be doing this*" [2]. There was difference in motivation in that his motivation was conditional. He said "*I'm there not because I have to. Cos I like to . It's a different thing*" [3]. Thus, when S4 did not sustain employment, this was often because he did not like his work place e.g. "*And in the end he did secure a job there but to my recollection he lost that job within about a week or two. And I, anecdotally, from what I was told about it, the issue was that there was people – people were swearing, people working there who felt you know , they shouldn't have been behaving in the way that they were behaving*" [4]

S5 had stated that he wanted to get back to work but both family and job coach felt that he lacked motivation [5]. However, like S4, he himself expressed conditional motivation (financial conditions): "*Obviously I wouldn't want to go back on lesser money than what I was getting on insurance because that would be a bit silly, but I would rather be working than not working*" [6]. His conditions were not met and he did not sustain employment.

It was felt that S6 lacked motivation [7] - however it was unclear if this was because conditions of motivation had not been found.

S7 was unconditionally motivated and this kept her employment sustained [8].
S8's father felt that the lack of responsibility kept S8 from being motivated to sustain employment. He said, "*I think that he – he packed that job in – he's not packed the job in because he's lazy and just wants to sit around. .. I've had words with him and said I don't think you're seeking employment hard enough*" [9]. He felt that S8 had overcome his sense of victimization: "*I think he did have a "Why me" type attitude. I think he's overcome that*" [10] but that he did not have a sense of responsibility [1].

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[1] Document '4E', Paragraphs 178-180
[2] Document '4E', Paragraphs 220-221.
[3] Document 'S4', Paragraphs 829-830.
[4] Document 'R4', Paragraphs 221-225.
[5] Document '5F', Paragraphs 598-599, Document 'R5', Paragraphs 79-81.
[6] Document '5E', Paragraphs 491-493.
[7] Document '6R', Paragraphs 149-151.
[8] Document '7R', Paragraph 303.
[9] Document '8F', Paragraphs 350-355.
[10] Document '8F', Paragraphs 212-213.

Thus, there is a clear indication that unconditional motivation was associated with sustained employment and that motivation based on conditions was associated with poorly sustained employment. A sense of responsibility was associated with motivation. In one case, overcoming a sense of victimization was associated with motivation and sustained employment. This was not the case in another individual with ABI.

Impact of anger management on sustained employment

Two cases (S5 and S6) were reported to have problems with anger management at work which affected sustained employment. S5 became fatigued and frustrated and "*once it started, (it) just spiralled – you know and towards the end of the day, the more tired he got, it spiralled quicker and he got more and more frustrated, more and more bad tempered*" [2] . This was an ongoing problem and it was felt that S5's anger management would continue to cause a problem if he returned to work [3].

S6 lost his temper with a manager and had to leave a previous job [4]. However S6 was able to control his anger and walk away from provocation and this helped him sustain employment the next time round [5].

Though there were reports of anger management difficulties at work or at home in the 3 other cases (S1, S2, S7), these were neither reported to have implications on sustained employment nor on work quality [6].

Thus, poor anger management was associated with poorly sustained employment in 2 cases.

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[1] Document '8F', Paragraphs 366-368.
[2] Document '5E', Paragraphs 423-429.
[3] Document '5F', Paragraphs 481-482
[4] Document '6S', Paragraph 659
[5] Document '6F', Paragraphs 82-86.
[6] Tree node: Anger management.

Impact of passivity on sustained employment

S4 was described as being so polite that he would not want to express dissent with his employers and his Rehab UK key-worker felt that this was a barrier to sustaining employment: "*His potential barriers to succeeding and achieving things was probably his personality, in that he was too polite to be as honest as he should've been ... instead of being so concerned about offending the team to been able to say, well, there's no way I can see myself doing that cos that's really complicated and I want to work on internal strategies to get my memory back. That might have been a better way forward. So I think that possibly his intrinsic politeness and sense of values and his sense of manners and how to get on with people might have actually held him back*" [1].

S5's passivity was an obstacle to sustained employment. His co-worker felt it was as if he wanted to have an easy life at work [2]

S8 was also reported to have problems with apathy [3] and it was felt that his pursuing of another job was less energetic than desired – he could "*push just a little bit harder*"[4].

The converse was true: S1 actively took initiative and this not only helped sustain employment but resulted in promotion as he could contribute more to the business and do more than what he was given a chance to do [5].

Thus passivity, being too polite and lack of drive were all seen to affect sustained employment in 3 cases (S4, S5, S8). Conversely, taking initiative resulted in sustained employment.

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[1] Document 'R4', Paragraphs 347-360
[2] Document '5E', Paragraphs 368-374; Document 'S5', Paragraphs 716-717.
[3] Document 'F8', Paragraphs 493-494
[4] Document 'F8', Paragraphs 516-517
[5] Document 'E1', Paragraphs 84-94.

Impact of an inflexible personality on sustained employment.

S4 saw things in black and white. He felt that giving and taking respect at work was more important than flexibility [1]. This inflexibility affected his ability to sustain employment when faced with co-workers who did not behave as he felt right: "P*eople were swearing, people working there who felt you know , they shouldn't have been behaving in the way that they were behaving and he complained about that and that made him very unpopular with everyone*" [2]. It also affected his work in a later job but did not affect sustaining employment for that job [3].

S5 had many problems with inflexibility but these were not associated with his poorly sustained employment. Most of the issues were around his inflexible suspicions about the motives of his company and managers. This was an obstacle to returning to work with them [4].

S2, S3 and S6 were reported to have problems with inflexibility but this neither affected work quality nor sustained employment [5].

Thus inflexibility affected sustained employment in 1 case, work quality in 1 case and was inconsequential in 3 cases.

Personality traits not affecting sustained employment

There was mention of a few other traits affecting quality of work (being oversensitive, over confident and inappropriate) but these did not affect sustenance of employment.

S4 found it hard to handle cheekiness and took it personally [6] if somebody was rude. He would take it to heart instead of "*letting it wash over*"[7]. S6 also reacted negatively

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[1] Document '4S', Paragraphs 767-770.
[2] Document '4R', Paragraphs 224-226.
[3] Document '4E', Paragraphs 27-34.
[4] Document 'R5', Paragraphs 189-192.
[5] Tree node: Inflexible
[6] Document '4E', Paragraphs 57-59
[7] Document '4E', Paragraphs 65-67

to any sort of criticism or teasing [1]. Their oversensitivity affected their ability to manage difficult circumstances at work, but there is no evidence of it affecting their ability to sustain employment. In fact, S4 slowly learnt to overcome this oversensitivity in the last job which he sustained [2].

S5 was reported to have difficulty with overconfidence and needed to be double checked at work. This will be discussed in the section on Twinning at work (having to work alongside another co-worker on the same job).

Inappropriate behaviour was reported in a few cases: inappropriate talk was reported in social situations but was not reported in their work situations [3].

S2 had a few problems socially [4] as his ability to read social cues deteriorated with tiredness [5] but again he could take correction in the right spirit and apologize and the problem did not happen again. It appeared to be a lack of recognition of appropriate social constraints with definite signs of improvement in S2 with time [6].

S3 and S6 had similar problems but these did not impact work. S6 would frequently make comments without realising that he had said something untoward [7].

Some traits were also mentioned especially during the assessment stage in Rehab UK but these were not reported at work later on (sense of humour, intolerance and impulsiveness) [8].

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[1] Document 'F6', Paragraphs 87-89
[2] Document 'E4', Paragraph 228
[3] Tree node: Inappropriate conversation
[4] Document '2F', Paragraphs 158-161
[5] Document '2F', Paragraphs 295-296
[6] Document '2R', Paragraphs 76-77; Document 'E2', Paragraphs 188-189
[7] Document '3R', Paragraphs 58-59; Document '6R', Paragraphs 111-112.
[8] Tree nodes: Sense of humour, Intolerant, Impulsive

Thus, while being oversensitive, overconfident and inappropriate were reported in some cases, this did not affect sustained employment. Intolerance and impulsivenes were only reported in the preparatory phase in 2 cases and a good sense of humour was not associated with sustained employment.

THE IMPACT OF COGNITIVE ISSUES ON SUSTAINED EMPLOYMENT [1]

Data within the nodes relating to cognitive issues was examined for evidence relating to 2 questions:

- What cognitive features were directly related to sustained employment?
- What approaches to cognitive difficulties were directly related to sustained employment?

There were several issues raised about these questions which fall into 3 categories of cognitive factors described by the interviewees:

- Cognitive factors which have directly helped or adversely affected sustained employment. Occasionally where the individual or co-worker/line manager copes with these difficulties and the coping process is highlighted.
- Cognitive factors which have been reported in the individual which have helped or adversely affected quality of work, but not reported to have affected sustained employment.
- Cognitive factors noticed in the individual which have been reported not to have affected quality of work or affected sustained employment.

In addition there is one more logical category to complete the set i.e. Unrelated and absent data: Factors not reported to have affected quality of work or ability to sustain employment. When issues raised by one case study have not been raised by another, the reasons for this have not been explored. This is because of the semi-structured

[1] Analytical node: AN Cognitive after

nature of the interviews and the principle of allowing ideas to emerge from the interviewees rather than leading them to topics. Therefore when no association is described in this study, unless otherwise stated, this means that it was not looked for and not that it did not exist.

As there was a large amount of data which was inter-related in the nodes relating to cognitive issues, data analysis in this section is presented first in a case by case analysis. Cognitive issues were described by the triangulating set of interviewees in this approach. Then topics are categorised and a cross case synthesis is presented later.

Case by case analysis

Case 1

S1 reported several difficulties at work (selective attention, getting confused, multi tasking, visuospatial coordination) but found ways around those difficulties which helped him to sustain employment. He used insight and motivation to correct his difficulties. During the preliminary stage of the vocational programme training module, it was reported that he could become intolerant because of his inability to filter out background noise: "*He will be the first to concede that his tolerance levels have been affected and he would find certain client's behaviours very difficult to deal with. And in addition to that as well his ability to filter out background noise has been severely impaired, and so when some clients were perhaps not taking it seriously and were mucking about and having a laugh and S1 was trying to get on with his work, he found that very difficult to deal with because he couldn't blank it out*" [1]. He himself said that this was a problem which continued to distract him after he returned to work and that he had improved with time: "*There's some things that always confused me. I don't know whether its because you .. adapt to what you can do. I'm not obsessed by it now. Yeah? I was for a while. .. I used to get guarded if I were doing the talking and someone came in and was talking over us. I would automatically think I cannot handle this and obviously then I couldn't. Soon as I thought that I'd be distracted. My ability to cope with it is still improving. .. I have to do it. That's now been improved to*

[1] Document 'R1', Paragraphs 108-115.

be able to do dual or triple tasks, probably some working (gestures to how he handled the phone and computer) that is fine" [1]. As he had insight into this difficulty, he also requested and obtained a quiet office which helped him to sustain employment [2].
He also noticed that "*there used to be a slight delay when people used to ask me something before I answered. And I said that's because so much I think. I find it difficult to understand but I was actually thinking of the response*" [3]. Also, he said he had "*major, major problems on was double sided sheets*" [4] because " *You've got turn it right and then turn it round and John* (IT trainer) *was saying, well I'll do something. I'll do it single sided for you. Fine, but I'm not going to learn in the real world like this. So I have to think about it. Now you see I'm alright. The major thing was then. Now I'm here its actually quite small. But at the time, I just could not understand why they did silly things like that, you know"* [5].
But S1 was very careful both in recognizing these difficulties and with every step of his employment process [6]. He was able to learn and apply knowledge in the work place as well. He also used external aids to help him, "*making numerous notes, just in case*" [7]. He transferred what he had learnt in the training modules of the vocational programme to the work place and it was said: "*I think what he gained very quickly was a clear understanding of how work he does in the centre will transfer into a work placement and will transfer into employment and how he can use the knowledge and transfer it into a real situation. Some clients struggle with that, some clients come into the programme and can't see how doing this cognitive exercise is going to help me along the way. But S1 could quite clearly conceptualize that. So he did progress well and progress quickly"*[8] . Also, S1 had no problems with fatigue and in fact his co-worker reported that he worked far more extra hours than he wanted to without any problem [9].

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[1] Document 'S1', Paragraphs 484-493.
[2] Document 'S1', Paragraphs 151-155.

[3] Document 'S1', Paragraphs 512-515.
[4] Document 'S1', Paragraphs 542-543.
[5] Document 'S1', Paragraphs 545-551.
[6] Document 'F1', Paragraph 755.
[7] Document 'F1', Paragraphs 921-922.
[8] Document 'R1', Paragraphs 93-100.
[9] Document 'E1', Paragraphs 356-357.

Thus, cognitive difficulties of slow processing speed, multitasking and visuospatial difficulties were the cognitive difficulties which directly affected S1's work. But S1 carefully recognized this and acted to compensate for these difficulties by using his new learning and adapting abilities, by using external aids and by obtaining a quiet office. Fortunately, he did not have difficulties with fatigue and often worked harder than his colleagues.

Case 2

S2 had difficulties with short term memory, attention and concentration. This was specifically addressed by S2's employer. He knew S2 would forget things from a list especially if they were not part of S2's routine [1]. He knew that S2 could "*drift away*" i.e. he could not pay attention to instruction [2]. So he did not overload him but gave him one job at a time rather than a list of jobs. Thus he changed his supervisory methods by giving him serial instruction for new jobs and structure for repetitive ones[3]. This helped S2 to sustain employment.

S2 had stopped using external aids for memory: "*S2 has gone out of the habit of writing everything down in his diary and working from that, determined to prove... he has a perfectly good memory and that he can do the same as everybody else*" [4]. However, at work he devised his own compensatory mechanisms to help him out with memory e.g. triggers to remember things (rather than cues): "*you were doing this, you were doing that. And then I can remember. Its like a trigger that tells me, reminds me, oh, that's what I was doing* [5]*..... Key words and places* [6]*....if I don't know the way, but I would always cover up and make sure that they have .. I'll make sure that they certainly have a sort of, I can.. a bit of my memory comes back, suddenly remember, I can remember it (the way back), yeah*" [7].

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[1] Document 'E2', Paragraphs 283-290.
[2] Document 'R2', Paragraphs 272-273.
[3] Document 'E2', Paragraphs 283-290.
[4] Document 'F2', Paragraphs 799-802.
[5] Document 'S2', Paragraphs 77-79.
[6] Document 'S2', Paragraphs 85-87.
[7] Document 'S2', Paragraphs 90-93.

S2 could remember doing a task but would insist that he had done it on a different day than what actually happened [1] i.e. he had problems with confabulation – he placed memories in the wrong time [2]: "*S2 can remember something incorrectly which he turns into fact and swears his life on it and he's quite convincing to other people as well – so he confuses everybody, confuses himself and just, its most frustrating time and time again when that happens. So we have to watch that his memory along with his judgement of things is correct. We have to watch that*" [3].

This confabulatory memory was not only retrospective, but also appeared in new learning tasks and affected his summer work where he was self employed and worked from home: "*Instead of going off in that direction, to do a job .. he got it into his head that he was going back to this other place. And he went and did the whole of the area for the fellow again and it wasn't part of the deal. So the money he's earned on that he completely blew – a waste of time and trouble*" [4]. However it did not prevent him from sustaining employment.

S2 also had a fixed (perseverative) way of thinking at times which might have had an impact on his work and his parents said, if "*He's got to do it there, he's got to do it then. And in a certain way. And he'll just be obsessive about it*" [5]. His employer also agreed: "*he does get his mind fixed where S2 decides to do something – that's it*" [6].

S2 had problems with mental (rather than physical) fatigue which affected his work but his employer would give him an appropriate break: "*If the season is too long for S2, he gets very tired in that he sometimes mentally he gets wound up sometimes. And we've developed a – we send him home in February to break up the season for him. So we send him home for 2 or 3 weeks of rest and then he comes back refreshed. I do think a continuous season he would get so tired that – when he gets tired he becomes fairly ineffective really. He's just mentally lost it so to speak*" [7].

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[1] Document 'F2', Paragraphs 837-841.
[2] Document 'F2', Paragraphs 844-845.
[3] Document 'F2', Paragraphs 851-856.
[4] Document 'F2', Paragraphs 873-878
[5] Document 'F2', Paragraphs 989-990.
[6] Document 'E2', Paragraphs 68-70.
[7] Document 'E2', Paragraphs 242-249.

S2 himself took breaks like afternoon naps for 2-3 hours when he recognized this [1]. Though his physical energy levels were excellent (he could cycle 60-70 miles [2]), he did become physically tired when he developed mental fatigue: "*When S2 is physically tired, he becomes mentally tired, like a vertical graph, so just suddenly happens (whistles sharply, gesturing a sudden drop) – just drops of. Its gradual to begin with, steeper than would be for us, woof, just drops. Now when he is .. and the converse works, when he's mentally tired, he has no physical energy*" [3]

He had difficulty with organization and could be quite haphazard[4] but this was not reported to have an impact at work. He had some difficulty with clarity of speech but again this was not noted to impact on work as he actively attempted to make himself clear [5]. S2 was able to recognize his cognitive difficulties and used a combination of humour and honesty to cope with people at work [6]. However, he did not feel that his problems were as severe as they really were [7].

Thus, S2's difficulties with short term memory, attention, confabulation and perseveration affected his work, while poor organization and poor clarity of speech were not reported to affect work.

Though he had insight into his problems, S2 had not actively compensated for them except for fatigue. In fact he stopped using external memory helps and preferred to use less dependable memory triggers at work. However, his employer had organized S2's work in such a way that these did not impact on sustained employment i.e. he was given a fixed set of jobs and if new jobs were added, these were requested one after the other. He also arranged appropriate breaks to manage fatigue.

Case 3

S3 had great difficulty with short term memory especially when he was required to do several things at work. His manager said that he "*gets distracted more from what he's*

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[1] Document 'E2', Paragraphs 257-261.
[2] Document '2F', Paragraph 219.
[3] Document '2F', Paragraphs 196-201.
[4] Document 'R2', Paragraphs 14-15; Paragraphs 29-30.
[5] Document 'S2', Paragraphs 444-449.
[6] Document 'E2', Paragraphs 110-114.
[7] Document 'R2', Paragraphs 191-193.

supposed to do and doesn't return to do it at all" [1]. His father said that "*He's had some problems keeping his mind on the right thing. Or, they call it multi tasking here, umm where he's doing a job, whenever the public ask some directions, he gives that member of the public directions and forgets to the job he was on in the first place*" [2].

In addition to his short term memory difficulty, he had an inability to switch attention which was affecting his work adversely as his job coach described: "*He was maybe stacking shelves and the customer would ask him where the candles were. He was very appropriate with the customer, would go over and show the customer where the candles were. But then he wouldn't return back to his original task*" [3].

An attempt to modulate this loss of short term memory with external aids like a reminder card or a dictaphone did not help because he would forget to use them [4]. So S3's manager who changed his place of work and then reported success because it was a smaller department and "*It was easy to bring him back to what he was supposed to be doing*" [5]. He could manage to recall information with cues. His father said, "*If you give him a cue, he'll come up with it. I used to try this with the football team. I use to try this with the football team. I used to give him the first names, and he would come up with the surnames. But ask him to name them* (gestures no use)" [6]. But there is no evidence of this being used at work.

His learning skills stood him in good stead at work as his manager described: "*But you have to know where everything within the store was you know, which he did pick up on, did learn quickly, did learn new information*" [7].

But S3 had the additional problem of being unpredictable and sometimes did not realize it was happening: "*Sometimes he looks a bit blank, he has no idea. Other times*

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[1] Document 'E3', Paragraphs 40-41.
[2] Document 'F3', Paragraphs 444-447.
[3] Document 'R3', Paragraphs 241-245.
[4] Document 'E3', Paragraphs 257-266, Paragraphs 50-53.
[5] Document 'E3', Paragraphs 54-58.
[6] Document 'F3', Paragraphs 77-81.
[7] Document 'R3', Paragraphs 333-335

he remembers that he should've been doing that and says, Aww, I could kick myself. I'll go back and do it now" [1]

Also he did not know when he needed to ask for help with difficulties [2]. It was felt that his insight, though present was superficial [3]. But he himself had a realistic self evaluation though there is no evidence of acting on this realization [4].

S3 also had difficulty with confabulation but this was not reported to have an impact on work. His father reported that "*He quite often says that he's done things that he hasn't*" and would not accept the actual fact [5].

His organizational skills were also affected [6] though this did not seem to have a direct impact at work.

He also had difficulties with impulsiveness and this affected reading and tasks which again did not appear to impact on work [7].

Thus, S3's difficulties with short term memory, switching attention and initiation affected his work. However his new learning ability helped the situation. Though he had difficulty with organization, confabulation, impulsiveness, these were not reported to have affected sustained employment.

S3 had some insight into his difficulties but did not act on it. He stopped using external aids and it was his manager who then placed him in a different environment which helped him sustain employment.

Case 4

S4 was reported to have problems with organization and planning when he was in the programme [1] and this became a problem when he tried to sustain a very busy job as a

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[1] Document 'E3', Paragraphs 71-73.
[2] Document 'R3', Paragraphs 165-171.
[3] Document 'R3', Paragraphs 341-345.
[4] Document 'S3', Paragraphs 351-357.
[5] Document 'F3', Paragraphs 289-290, Paragraphs 204-212.
[6] Document 'R3', Paragraphs 18-19, Paragraphs 27-30.
[7] Document 'R3', Paragraphs 225-232.

head chef: "*When orders came in thick and fast and he struggled to keep on top of it he panicked. Rather than put his hand up and say I'm struggling here, he would go off and start washing vegetables or doing something else. The orders would pile up. The workforce was thinking, why is the head chef washing tomatoes, That's for the junior member of staff to do*" [2]. However, S4 was very aware of his limitations [3]. But rather than follow the vocational programme's advise of using compensatory techniques and applying strategies, he attempted to exercise his memory and "*he fought to try and get his memory back*" [4]. It was only much later on – after going through several episodes of poorly sustained employment, that he began to use a notice board at home to remind him of his appointments [5].

Thus, apart from problems with organization which initially impact on sustaining employment, there was no evidence to show that S4 had problems with cognitive function later on. He did not use available resources at first, but later he did use external aids to help him though not at work.

Case 5

S5 realized that his concentration was affected. He would lose track in a conversation[6]. His lack of attention to detail was affecting his ability to sustain employment [7].

It was possible that what S5 was reporting as lack of concentration might be lack of ability to divide attention or switch attention as his daughter noticed that when he became very engrossed in something, he could not switch attention at all [8]. But his co-worker's attempts to discuss this with S5 were impossible: "*I approached the situation with him. And he nearly snapped me head off. And I just said to him, look I says, you know, we sat down , we had a heart to heart, off the record, nothing to do with work and all this. And I said to him. I says, I'm not after your job, ... he got annoyed*" [9] . He felt that others were to blame for his inability to sustain employment:

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[1] Document 'R4', Paragraphs 144-145.
[2] Document 'R4', Paragraphs 200-205.
[3] Document 'R4', Paragraphs 100-102.
[4] Document 'R4', Paragraphs 180-183.
[5] Document 'S4', Paragraphs 864-868.
[6] Document 'E5', Paragraphs 538-540.
[7] Document 'S5', Paragraphs 128-133, 43-44, Document 'E5', Paragraphs 273-279.
[8] Document 'F5', Paragraphs 434-436.
[9] Document 'E5', Paragraphs 234-239.

"*I think he thinks that the world's changed rather than he's changed. You now he's very critical of RV, the fact that they cant place him*" [1]. Sadly, all this affected his ability to sustain employment. [2].

His co-worker reported that S5 also had severe problems with mental fatigue which affected his ability to sustain employment. The mental fatigue worsened through the day: "*Because he would come in on the morning, and he's be spot on. I mean there would be no problem with him whatsoever. Very switched on, very motivated, liked to know what he was doing. By the time we got down to say like dinner time-ish, you could see that he was tired. You could see the look on his face that he was tired. By the time he got round to like, 3, 4, 5 o clock, he was absolutely dead on his feet*" [3]. He also reported that this fatigue worsened as he got through the week: "*and as the week progressed, as you started hitting Thursday , you – Monday morning, you were totally, he would be OK, till just after dinner. Tuesday morning up to like dinner time. Wednesday morning before dinner, until you got to Friday, and you know – it was very hard work on the Thursdays and Fridays. Because he was tired most of the day*"[4]. However there was no evidence that this problem of mental fatigue was addressed even though it impacted his ability to sustain employment.

His physical energy levels were not a problem and he was quite fit and could cycle up to 20 miles a day [5]. S5 had a good memory [1].

Thus, S5 had problems with poor attention and concentration and fatigue which had an impact on sustained employment. Even though he recognized these problems, he resisted attempts to allow compensation and felt that others were to blame for the problems. He was not able to sustain employment.

Case 6

S6 had difficulty with following oral communication and in fact during his interview, S6 would often lose track of the conversation and once even stopped suddenly when

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[1] Document 'F5', Paragraphs 281-282.
[2] Document 'E5', Paragraphs 280-284.
[3] Document '5E', Paragraphs 223-228.
[4] Document '5E', Paragraphs 393-398.
[5] Document 'S5', Paragraphs 520-530, Document 'F5', Paragraphs 402-405.

he experienced a severe, brief (post traumatic) headache. His girl friend said that with verbal instructions, "*He would either totally do the wrong thing or miss something out*" [2].

His memory was acceptable [3]. But S6 had difficulties with confabulation. He found it difficult to described this difficulty: "*I tend to make things up. I tend to not make things up – I done that. I don't know. I just kid meself that something might happen or could be – I don't know how I do it – just ... like ask me and I'll say no. like that. ...*" [4] Like S2, this problem was also with regards to recall of previous events in the wrong time slots without it affecting his employment. S6 said, "*I haven't got memories in time. I've just got memories. Can't tell between time*" [5]. His girlfriend agreed that he put memories in the wrong time slots [6]. In addition, he experienced episodes of "déjà vu" frequently – he would often "recognize" a stranger's face as someone whom he felt he had met before and be very convinced of it [7]. These problems with confabulation were one of the reasons why he could not sustain employment. His girlfriend described one such episode at work: "*When he worked at the pub he had – he had had a number of arguments with the manager. Mainly to do with his – erm, his time keeping and his memory and his manners with the customers. They would say that they'd given him a 20 pound note and they would have clearly given him a 10 pound note. But because he was quite fixed, he'd be determined that he was right*" [8].

S6 had difficulties with fatigue. He reported this as a problem in his previous job which he was not able to sustain. He did not attempt to take breaks or address the fatigue problem. He would then find that when he got tired, his speech slurred and that he started to miss things out [9].

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[1] Document 'S5', Paragraph 199.
[2] Document 'R6', Paragraphs 176-177.
[3] Document 'R6', Paragraph 65.
[4] Document 'S6', Paragraphs 356-364.
[5] Document 'S6', Paragraphs 530-531.
[6] Document 'F6', Paragraphs 3-6.
[7] Document 'F6', Paragraphs 22-34
[8] Document 'F6', Paragraphs 72-81.
[9] Document 'S6', Paragraphs 670-672.

S6 needed help with organization too [1]. Also he did not get one of his jobs because he failed an aptitude test [2]. Some of his difficulty may have been related to his previous dyslexia. His girlfriend used to do a lot of his letter writing if he had to apply for something [3]. Though he has difficulty finding his way for work, he used compensatory techniques: "*I mean he does – he can go somewhere. And go there Every day for a week. And then he's have the weekend off and if he has to go to the same place on Monday, he might find it more difficult to find. But as long as he has his A to Z with him and an address, he can usually find it. And he tends to leave earlier*" [4].

But he had no problems with multi-tasking at work: "*It was a place that served meals and doubled as a pub and was very busy and there was loud music all the time. He had no difficulty coping with two tasks at the same time*" [5]

Thus, S6 had difficulties with understanding oral communication, confabulation, fatigue and therefore, general aptitude. These impacted on his ability to sustain employment. However his memory and multi tasking abilities were intact. His problems with organization, multi-tasking, previous dyslexia and visuospatial skills did not impact on his work.

S6 used compensatory mechanisms for visuospatial skills which helped him sustain employment.

Case 7

S7 could not recognize numbers if she heard them making it difficult for her to manage phones at work and created a lot of anxiety at work: "*But you know like, working, I'm supposed to take me phone calls to customers. And I just cant do it. Because you know I get the type all mixed up*" [6]. "*What number did you say it was? He said to me, something "Ba ba ba ba ba". I says to him, eh? And he went at it*

[1] Document 'F6', Paragraphs 133-135.
[2] Document 'F6', Paragraphs 407-408.
[3] Document 'R6', Paragraphs 22-26.
[4] Document 'F6', Paragraphs 102-106.
[5] Document 'S6', Paragraphs 654-656.
[6] Document 'S7F7', Paragraphs 14-21.

again" [1]. *"I can't understand the telephone, I can't think of numbers on the phone. I've told people"* [2]. Her job coach tried to get around her difficulty with phones with various strategies but was unsuccessful [3]. So her manager organized her work so that she did not need to use phones [4]. She also made it possible for her to access appropriately modified promotion examinations [5].

Fortunately S7 had no difficulty with written data which was useful at work [6]. She also has word finding difficulties which did not impact on work [7]. She had a good memory. This was vouchsafed by her manager: "*Her memory I would say – its not bad. Its better than mine*" [8]. She had good ability for new learning which was useful at work [9]. And she retained her creativity, organization and initiative which was useful at work simulated activity in the vocational programme. She was also good at using strategies [10]. She used a notebook to aid her at work [11]. S7 had a problem with attention and concentration. None of these came in the way of work or sustaining employment[12].

S7 noticed difficulty with fatigue and worked part time to accommodate to her energy levels and was able to sustain her work: "*I'm working 5 days a week, 4 hours a day.... I mean I do get tired into the afternoon*" [1].

Thus, S7 had difficulty understanding spoken numbers though she did not have this problem with written numbers. This caused difficulty with answering phones. She however had good new learning, creativity, organization and initiative. Though she had poor attention and concentration and word finding difficulties, this was not reported to have an impact on sustaining employment.

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[1] Document 'S7F7', Paragraphs 435-437.
[2] Document 'S7F7', Paragraphs 196-198.
[3] Document 'E7', Paragraphs 95-138.
[4] Document 'E7', Paragraphs 213-222.
[5] Document 'E7', Paragraphs 228-234.
[6] Document 'E7', Paragraphs 37-43.
[7] Document 'S7F7', Paragraphs 222-231.
[8] Document 'E7', Paragraphs 203-204.
[9] Document 'E7', Paragraphs 16-21.
[10] Document 'R7', Paragraphs 70-74.
[11] Document 'E7', Paragraphs 101-103.
[12] Document 'S7F7', Paragraphs 582-584, 190-192.

S7's employer arranged not only for her to work without using a phone, but also to be tested for promotion without having to hear numbers. S7 also used external aids to help sustain employment. In view of her difficulties with fatigue, she reduced her hours of work and sustained employment.

Case 8

S8 did not have problems with attention and concentration [2]. Indeed cognitive difficulties were not a problem with S8 except for the loss of memory of events before his accident (long term memory) [3]. But there was no evidence that this had an impact at work.

S8 reported fatigue but this did not affect work quality and he actually worked long hours and it might have been physical fatigue from the hard work rather than ABI related fatigue [4].

Thus, S8 was not reported to have cognitive difficulties which had an impact on sustaining employment.

Outline of cognitive difficulties mentioned in the data – Cross case synthesis

Not all cognitive functions earned a mention by interviewees. The list of cognitive difficulties mentioned by interviewees are summarised here:

1. Short term memory: This affected sustained employment in S1, S2 and S3. In all these three cases who sustained employment, individuals used coping strategies - external aids - either note books, diaries, cues or, as in one case, triggers.

2. Attention and Concentration: This affected sustained employment in the case of S2, and S5. Switching attention between tasks affected employment in S3. Poor

[1] Document 'S7F7', Paragraphs 500-506
[2] Document 'S8', Paragraphs 484-487, 23-24.
[3] Document 'S8', Paragraphs 31-36, Document 'F8', Paragraphs 19-21.
[4] Document 'S8', Section 0, Paragraphs 481-484; Document 'F8', Paragraphs 162-165.

attention and concentration, though present, did not affect S7's sustained employment. Thus there is no emerging pattern for this in sustaining employment.

3. Confabulation: This affected sustained employment for S2 and S6 but not for S3. It was described as the conviction as a result of a memory placed at the wrong time. Thus there is a variable pattern linking confabulation to sustained employment.

4. Fatigue: This was more mental than physical fatigue and it affected sustained employment for S5 and S6. However when compensatory approaches were used (S2 and S7), fatigue did not come in the way.

5. Retained new-learning skill was described to have helped sustained employment in S1, S3 and S7.

6. Insight was reported to be present in S1, S2, S3, S4, S5 and S7. However this recognition only proceeded to action in those who sustained employment i.e. S1 and S7. S4 and S5, who could not sustain employment, did not act on their insight. S2 only partially acted on his insight while S3 did not act on his insight. Though S2 and S3 sustained employment, their employers had taken cognizance of their cognitive difficulties and modified their work patterns to compensate their cognitive difficulties.

7. Poor organization and planning affected sustained employment only in S4. Though poor organization was described in S2, S3 and S7, this was not noted to impact sustaining employment. S7 was noted to have good organization and planning skills helping to sustain employment in her case.

8. Processing speed was reported to have an impact on work (but not on sustained employment) only by S1.

9. Visuospatial difficulties affected work in S1 but not in S6 who used external aids to find his way around. However there was no association with sustained employment.

10. Perseveration affected S2's work but did not affect his sustaining employment.

11. Poor multitasking abilities affected S1 and S5's work but not their sustained employment while S6 had good multitasking abilities.

12. Inability to understand oral communication (S6, only numbers for S7), previous dyslexia (S6) and word finding difficulties (S7) were not reported to affect work or sustained employment.

13. Long term memory difficulty was the only cognitive difficulty reported by S8 and this memory loss was specifically before his accident. This was not reported to have affected his work - there were different reasons for his poorly sustained employment.

IMPACT OF PSYCHIATRIC ISSUES ON SUSTAINED EMPLOYMENT [1]

The only issues raised by interviewees in some of the case studies with regards to psychiatric issues were relating to Paranoia, Depression and Alcohol related problems. The data was again subjected to these 2 questions:

1. What features were directly related to sustained employment?
2. What approaches used to combat these difficulties were directly related to sustained employment?

Again responses from interviewees fell into the following categories:

1. Factors which have adversely affected sustained employment and the way the individual or co-worker/line manager coped with these difficulties are mentioned.

[1] Analytical node: AN Psychiatry after

2. Factors which have adversely affected quality of work but not reported to have affected sustained employment.
3. Factors noticed in the individual which have not been reported to have affected quality of work nor been reported to have affected sustained employment.

Unlike cognitive factors, these issues were rare, isolated occurrences and had not been reported to inter-relate with each other. There were exclusion criteria operating in Rehab UK with regards to alcohol (and in general substance) abuse which meant that individuals with unresolved continuing alcohol or drug problems would not be accepted on the programme. Therefore a cross case synthesis rather than a case by case analysis is presented below.

Impact of Paranoia on sustained employment

S5 felt that everyone was against him. This was not the case but this belief resulted in an inability to sustain employment, as has been shown in previous sections. Also in the previous section was the instance where this was attempted to be set right both by job coach and co-worker, but S5 could not overcome this belief. His co-worker said, "*He would do things and forget he'd done them. He would swear down blind he'd told somebody to do something and they haven't said nothing to them. And I think he honestly thought that the whole of the body shop was sort of playing a trick on him*" [1]. *And of course, he found it very hard to believe that he was wrong. Or he'd made the mistake. And he got very frustrated through it. And then the powers that be deemed that it was not right for him to be working alongside me-self in the situation that we were in.*" [2]

S6 also had 'conspiracy theories' but laughed about it: "*R: Do you tend to think that people are against you? S6: Yeah (laughs). I'm in trouble for that*" [3]. *Yeah. I always get conspiracies (laughs). .and that. I want to get this conspiracy – I know – I always get conspiracies. I know, I always .. But I'm trying to get out of that now*" [4]. He

[1] Document 'E5', Paragraphs 244-247.
[2] Document 'E5', Paragraphs 281-284.
[3] Document 'S6', Paragraphs 465-468.
[4] Document 'S6', Paragraphs 474-476.

recognized them to be false and had been able to overcome them and this has not been an issue at work.

Thus the impact of paranoia was different in these 2 individuals who deal with paranoid thoughts very differently: it affected sustainability of employment in one who acted on it while paranoia was not even reported to affect the work of the other who tried not to act on it.

Impact of Depression on sustained employment

S4 experienced depression through his time with Rehab UK as a result of personal and financial issues. This had a direct impact on his placements as S4 decided that he was unable to commence this placement [1].

No other case studies reported sequelae of psychiatric symptoms after ABI except S8 who reported that he was depressed during the acute stages of physical rehabilitation before he could walk again.

Impact of issues relating to Alcohol on sustained employment

S2 would become inebriated on small amounts of alcohol. This had an impact on work and also made him vulnerable at work, as his employer said: *"Sometimes, we have had on occasion people will go to S2's table because they know they – S2 will give them everything they want. If they want to get drunk at the table, S2 will get them enough wine to get drunk. And I feel they're using him for that situation. They know that he's slightly different, but it's a convenient way of using somebody. The other group who are great friends with him, don't appreciate that he shouldn't drink too much and they're forever buying him drink… They think they're being great pals with him and help – being nice with him, but in fact, they're not doing him any favours if he has too much to drink….And he quickly loses control – his table manners deteriorate, just very rapidly if he's had too much to drink. And he gets louder as well.*

[1] Document 'R4', Paragraphs 233-237, Document 'S4', Paragraphs 303-304.

And he can become embarrassing sometimes, if he has had far too much" [1]. S2's judgement was affected by alcohol [2],[3].

His employer therefore, recognizing this, made stipulations on his alcohol intake at work and this helped prevent difficulties. "*we banned him from alcohol before dinner .. after a particular incident ... I don't like totally banning him from alcohol, but in a way, before dinner, I don't want him to have had too much to drink... So what we will probably do this season – experiment and say, you're allowed one drink before dinner S2, if you get too much to drink before dinner then we're going to have to ban you totally. And we'll see how that works out. That is our main problem with S2, is having too much alcohol*" [4]. But while this has affected work quality, it has not had an impact on sustained employment because of S2's employer's intervention.

S3 [5] and S6 [6] had some difficulty with intolerance of alcohol but this did not impact work or sustained employment.

S5 probably had a problem with alcohol but this did not have an impact on his placements and was not indicated as the reason for his poorly sustained employment and, in fact, the problem started after he stopped working [7].

S7 [8]and S8 [9] reported no difficulties with alcohol and S1[10] did not touch alcohol after his ABI.

Thus, while intolerance to alcohol was a problem in some individuals with ABI, it impacted work quality but not sustained employment. When provision of alcohol was

[1] Document 'E2', Paragraphs 122-127, 127-129, 130-132, 138-150.
[2] Document 'F2', Paragraphs 301-302.
[3] Document 'F2', Paragraphs 310-313.
[4] Document 'E2', Paragraphs 154-155, 138-150.
[5] Document 'F3', Paragraphs 335-336, Document 'S3', Paragraphs 393-400.
[6] Document 'F6', Paragraphs 388-389, Document 'S6', Paragraphs 688-691.
[7] Document 'F5', Paragraphs 364-368.Document 'R5', Paragraphs 129-134.
[8] Document 'S7F7', Paragraphs 568-578.
[9] Document 'S8', Paragraphs 310-313.
[10] Document 'F1', Paragraphs 477-479.

part of the job and when the individual would not accept that this was a problem, the employer controlled consumption at work, and this problem was sorted out.

Similarly, coping strategies for paranoia were directly associated with sustaining employment

WORK ISSUES AFTER ABI

The impact of coping skills on sustained employment

S1 had difficulties (see cognitive factors and behaviour and personality) with divided attention and tolerance as described by the vocational rehabilitation staff member: "*He will be the first to concede that his tolerance levels have been affected and he would find certain client's behaviours very difficult to deal with and in addition to that as well his ability to filter out background noise has been severely impaired, and so when some clients were perhaps not taking it seriously and were mucking about and having a laugh and S1 was trying to get on with his work, he found that very difficult to deal with because he couldn't blank it out*". [1]

However his co-worker testified that he was able to overcome these at work: "*we started off with what like the conference calls that each day at 10 o clock, they would ring up and there'd be people in America, people here, people in Scotland and like you know all sitting together, sitting there going through all these part numbers. So S1 would sit there, no problem at all, control these conference calls, answer their questions, this part's in, going to be tested. The other is tomorrow, that needs two days for result on this one, I can give you as soon as I finish the call with this one, and he's control that working. That is what he's doing for the last 6 months very successfully*". [2]

[1] Document '1R', Paragraphs 108-115
[2] Document '1E', Paragraphs 146-154

He was able to cope with this with the help of his key worker [1].

S2 had difficulty judging situations especially when he was tired and could be inappropriate (see personality and behaviour). However when confronted he would make sure that apologies were made and that it did not recur [2], thus demonstrating his ability to cope with this difficulty.

S2 also organized breaks while working to cope with his fatigue - the "coffee strategy" as he called it: "*So I always entail a coffee stop whenever I'm out instructing*" [3] - "*that was the place that I introduced the coffee strategy. (What's that?) The coffee strategy – you have a cup of coffee when you're getting stressed out, or you need a rest. You have a cup of coffee. Then you go and have a rest*". [4]

Again he had difficulty with short term memory and even though he stopped keeping a diary, he compensated for this by establishing routines at work [5] to such an extent that his employer said of him, "*S2 gets himself a routine and he is extremely dependable. S2 isn't there, there is something wrong.*" [6]

S3 had a difficulty with going late to work a few times [7]. But he compensated afterwards by making sure he had his rotas written down or even laminated [8] and by going early – sometimes even half an hour early [9].

S3 however did have a problem with not recognizing when he needed to ask for help and this continued to be unresolved. His job coach described this: "*instead of saying Oh, I just lost my notebook, I mean please help me or whatever, he would kind of bluff his way around it by going out and buying a new notebook and not letting anyone*

[1] Document '1R', Paragraphs 117-119
[2] Document '2R', Paragraphs 66-71, 76-77

[3] Document 'S2', Paragraphs 209-212
[4] Document 'S2', Paragraphs 622-625
[5] Document '2F', Paragraphs 799-802
[6] Document '2E', Paragraphs 276-277
[7] Document '3E', Paragraph 14, Document '3R', Paragraphs 224-225
[8] Document '3E', Paragraphs 25-26
[9] Document '3F', Paragraphs 420-422

know that he's lost his notes .. like a misunderstanding" [1]. "*Instead of approaching someone, even if I didn't know someone name, I still go to him and say, excuse me, can you just tell us where the vases are? He wouldn't do that. He would to just go and find it himself.*" [2] However this hesitance to ask for help might have been because he could not remember names of his colleagues [3]. Later discussion will show that this was resolved by twinning. So this did not affect his ability to sustain employment

S7 had difficulty with numbers but coped despite having to work with numbers by asking for help whenever necessary and writing it all down [4].

The other major difficulty was for S7 to answer phones as she had difficulty understanding spoken numbers. In the rare event when she does, again she has demonstrated her ability to cope with this difficult problem as described by her manager: "*there's been times when people phone or – and its – S7 just answer the phone for me. And she'll answer the phone. And she will try to – she'll write everything down. We says write down.(.. and that works?) It does, yes.*" [5]

S4 was unable to cope with his impulsivity till a later job where this improvement was noted and he was able to sustain employment as described by his manager, "I think he always wants to be like at breakneck speed and then he does calm down. But that's just my perspective. It's just everything in its own time. There's no need to rush. And he has calmed down a lot since he first started I think." [6]

However, S5's inability to cope with his fatigue and concentration skills and S6's inability to cope with his confabulatory memory difficulties also caused poorly sustained employment.

Thus we see S1, S2, S4 and S7 sustaining employment by coping with cognitive and behavioural challenges and overcoming them at work whereas an inability to cope with disabilities (S4 later on, S5, S6) resulted in poorly sustained employment.

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[1] Document 'R3', Paragraphs 154-157
[2] Document 'R3', Paragraphs 337-340
[3] Document '3R', Paragraphs 114-115
[4] Document '7E', Paragraphs 98-102, 108-110.
[5] Document '7E', Paragraphs 216-222.

The impact of enjoying work on sustained employment

We know from the discussion of pre-injury issues that S1 was very interested in the type of work he had done in quality control and sustained employment. He was bored and frustrated with the repetitive nature of his job[2]. His ambition was to be a project engineer. He was able to demonstrate his ability and moved "*from data input to controlling a reasonable project*" [3]. He enjoyed the role of a project engineer - designing a system around what was needed by the company and trouble shooting[4].

S2's pre and post injury interests were matched to his abilities for his winter job. He "*really loved hard working outside and real physical side of the work.*" [5] as well as skiing. His job coach reported "*he would've cleaned the chalet and done all that when people were out skiing. And he would've got a fair bit of skiing himself and he loved the evening. He loved all the banter and sitting at dinner and getting on with everybody and having a laugh*" [6]. He felt that it was a productive time [7].

S3 had an interest in computers and his employer gave him extra work on computers and this helped him sustain employment [8].

The necessity to be happy with work was also echoed by S6 when discussing a friend of his who was his model for sustaining employment [9]. S6 also said he was not able to sustain employment because his job "*got boring*" [10].

S7's job coach also reported about S7's sustained employment: "*she loves her job, its permanent but its part time, its perfect for her, she gets on brilliantly with all the people that she works with, you know, and no other problems*" [1]

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[1] Document '4E', Paragraphs 158-161.
[2] Document '1E', Paragraphs 80-82.
[3] Document '1E', Paragraphs 170-178.
[4] Document '1S', Paragraphs 73-77.
[5] Document '2R', Paragraph 51.
[6] Document '2R', Paragraphs 125-130.
[7] Document '2S', Paragraphs 399-400.
[8] Document '3E', Paragraphs 39-40, 145-148,182-183.
[9] Document '6S', Paragraphs 155-158.
[10] Document '6S', Paragraphs 668-670.

It was the same for S5: he considered jobs other than his original job unsatisfactory, reporting that, "*I don't know if I'd get much satisfaction, although I don't mind talking to folks like*" [2] . But going back to his original interesting job was not sustainable as the job requirements were very demanding [3].

S8 loved his work place too and he would go back there with his co-workers even on a night out or a day off [4]. However he could not sustain this employment because of increased demands from a new work environment and a supervisor whose way of supervision changed later on [5].

Thus, we see that enjoying work played a role in sustaining employment. However there are 2 negative case analyses here:

S2 hated gardening[6] but his summer job was mowing lawns. However, though he had not pursued a similar placement during his time in the vocational programme [7], he sustained his summer gardening job despite not enjoying it.

S4 was a restaurateur and therefore took up a job as a head chef. But he was not able to sustain employment as: "*It was clear from the onset that he hadn't really understood what his job role was. He was appointed to run that kitchen and he thought he was appointed as an assistant. When orders came in thick and fast and he struggled to keep on top of it. He panicked. Rather than put his hand up and say I'm struggling here, he would go off and start washing vegetables or doing something else. The orders would pile up. The workforce was thinking, why is the head chef washing tomatoes, That's for the junior member of staff to do. So we were working to sit down and say this is why we need to work in partnership. Work with us and we'll get an appropriate placement for you*". [8] So, an enjoyable job by itself was not sufficient to sustain employment.

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[1] Document '7R', Paragraphs 211-214.
[2] Document '5S', Paragraphs 791-792.
[3] Document '5E', Paragraphs 580-584.
[4] Document '8F', Paragraphs 879-883.
[5] Document '8F', Paragraphs 44-47.
[6] Document '2F', Paragraphs 763-766.
[7] Document '2R', Paragraphs 108-115.
[8] Document '4R', Paragraphs 198-207.

When S4 later worked in a place where he was happy, his employer said of him, "*I think he's quite happy doing what he does and part of life. And really when he stays on duty he's more or less in charge of his own kingdom. And I think that gives him that bit of leverage that he needs to feel he is an important person which he is to be when he is here by himself.*" [1]. S4 himself reported that he was happy in this job which he sustained [2].

Thus, on cross case synthesis,

1. All 4 individuals who sustained employment enjoyed their work (S1, S2, S3 and S7) but 2 who could not sustain employment also enjoyed their jobs (S4, S8).

2. S5 and S6 could not find a job they enjoyed. They did not sustain employment.

3. S2 sustained employment despite not enjoying his work.

Thus there is a variable association between enjoying employment and sustaining it.

Other work skills

There were other issues raised at work like good time keeping skills. In both the group which sustained employment (S2 and S7) and those who did not (S6), time keeping skills were present but not associated with sustained employment. S3 coped with his difficulties remembering his rota and time keeping and was therefore able to sustain employment despite not having this skill. Thus, time keeping skills helped work quality but was not associated with sustained employment [3].

S1 and S3 underwent training courses after employment which helped work. S8 also went back to college but this was before starting employment. S2 attempted to do a

[1] Document '4E', Paragraphs 118-121.
[2] Document '4S', Paragraphs 594-596.
[3] Tree Node: Time keeping skills.

course but could not finish it. However none of these events were reported to be associated with sustained employment [1].

Grooming was not a problem in all cases (not raised as an issue in Case 7). It was reported as being a problem only with S5, but this was not associated with sustained employment [2].

Thus, coping skills were associated with sustained employment. But time keeping skills, grooming and doing training courses after ABI were not associated with sustained employment.

The impact of Work Environment on sustained employment [3]

There were 3 main issues raised in the category or work environment:

- The presence of a supporting co-worker (Twin)
- The ability of an individual with ABI to be an outstanding employee and
- Difficulty going to and from work.

These are discussed below.

Twinning [4]

Twinning is the process of providing a supportive co-worker to work alongside the individual with ABI. This process was not an integral part of the vocational rehabilitation programme but was used by employers instinctively and successfully.

There were S2's parents who had to supervise his summer job – performing the role of twinning [5] because as his mother said, "*If S2 was left to his own devices, S2 struggled with that. And if I got more time to the day to day running – tried not to do it but – I do try not to do it, but just to help him get over day to day*" [6]. This was also confirmed by his job coach, who said, "*And he really needed a support from his mum*

[1] Tree node: Post-morbid education.
[2] Tree node: Grooming issues.
[3] Analytical node: working environment.
[4] Tree node: Twinning at work.
[5] Document '2F', Paragraphs 117-121.
[6] Document '2F', Paragraphs 945-947.

and dad. They would've said to him, right, you've got to go to Mrs so-and-so's house to cut her grass tonight at 6 o clock. And then go to somebody else's. He just didn't." [1]

S3's employer battled a previous twin who felt that it took too much time despite getting financial help for extra hours (4 hours a week are paid as incentive). Finally he had to be transferred to a department where the twinning role was willingly done by the rest of the team – a lot of men of S3's age [2]. Though S3 still did wander off, he felt that this was a useful technique and that it helped sustain employment [3]

Twinning did occur in those who could not sustain employment (S6 and S8) and was associated with the times when they had been successful in sustaining employment. S6's girlfriend said, "*like you said the last time, the fact that he is working with somebody I would think helps him. He is not sent off to do his own thing. But he actually works for this person all the time. So he seems to be doing alright.*" [4]
In addition she felt that his work with the Territorial army was sustained for the same reason [5]. S8's father also looked back to the time when S8 sustained employment when he worked under the guidance of another person. He said, "*the first year he was there he was under the guidance and learnt an awful lot under one particular guy – I think Mick*" [6].

There were no negative case analysis i.e. cases of twinning associated with the process of poorly sustained employment. Thus twinning is associated with sustained employment in S2 and S3 and in the episodes of sustained employment of S6 and S8.

Being an outstanding employee [7]

S1, S2 [8] and S4 were described by their co-workers or managers as being outstanding employees. S1's co-worker said, "*He's probably the only man I've ever worked with that I haven't had an argument with or any hassle... Yeah he's been a smashing bloke*

[1] Document '2R', Paragraphs 145-148.
[2] Document '3E', Paragraphs 118-130, 257-267.
[3] Document '3S', Paragraphs 285-294.
[4] Document '6F', Paragraphs 49-52.
[5] Document '6F', Paragraphs 416-417.
[6] Document '8F', Paragraphs 67-69.
[7] Tree node: Now an outstanding employee.
[8] Document '2R', Paragraphs 30-31.

to know and work with. I've no problems with him whatsoever, probably one of the best men I've ever worked with and I've worked for 5 companies, I've worked with some right pratts and I've worked with some decent people and he's one of them. No problem with, I trust him 100%, excellent..... S1's input on that job was really, really valuable." [1] S2's manager said, "*S2 is extremely popular with the clients ... he's good fun, amusing character, he's a great character.. From a business point of view, I think, most of our clients are highly appreciative of him being there.. he is extremely dependable. S2 isn't there -there is something wrong."* [2] Even though S4 had not sustained employment, this is not a negative case analysis as S4's employer all refer to a job which he had been able to sustain. She said, "*I find S4 very competent, he's very loyal to me which obviously is what I need cos he's here on his own. He's very honest, he's trustworthy."* [3]. Thus it is interesting that individuals with severe brain injury and persisting sequelae who had found it difficult to return to work in the initial year after injury were now described by their employers as great, competent, extremely popular with customers and extremely dependable.

Travelling to and from work [4]

There were several reported issues with travelling to and from work.

S1's father said that travelling long distances to work was very tiring [5]. S1 actually moved town closer to work to sort this issue out. This was despite being able to drive.

S2 had no difficulty travelling and said this helped him to reach work [1]. He could drive.

S4 could not sustain work because of his difficulty getting to and from work. He could not return to driving because of a visual difficulty following the ABI and had difficulty especially on weekends and late nights and especially if he finished work late. He described his difficulties (as English is not his first language, explanatory words are enclosed in this quote (non-italics) to give the context): "*There were 2 jobs*

[1] Document '1E', Paragraphs 46-47, 184-185,367-372.
[2] Document '2E', Paragraphs 63-68, 70-71, 72-78, 275-277.
[3] Document '4E', Paragraphs 97-100, 231.
[4] Tree node: Getting to and from work.
[5] F1, Paragraphs 847-848.

*I was interested. But first thing I was asked for driving licence. Didn't go for that job because of that. (Does it affect the amount of hours you can work? Working late at night and things like that?) Just now I remembered another thing. .. I was working in the restaurant or kitchen since 11 o clock at night. Caught a bus perhaps taxi and go home. Getting too expensive. That's why I changed pattern to do a night shift because there is a bus to get there and mornings there's a bus to go home. I changed my life around to fit the things I wanted to do as well. Because if I was working in the ****,, I could be the head chef, I can run the restaurant or the bar, but I don't want it because Sundays was out of the question. I missed 2 Sundays in church and I wasn't happy at all. And they find out that.* (Of) *course, I let them know I wasn't happy at all. I said that* (should never) *happen again* (or) *I'll just go and I don't comeback.*(It will) *Never happen again. Second time. I'm not happy.* (They say) *Oh, I take you to the church, you go night time and .. No, no. Now its too late. Service started already. I'm not .. I wasn't there this morning, I wanted to go.* (Its now) *Quarter to 8 , service started, a prayer meeting and service starts half past 7. I not go ..*(others will) *get disturbed,* (when I) *get there when everyone is praying,* (they will) *start looking back. I'm not happy I'm never happen again.* (They say) *Alright, alright, alright. This was at the* ****" [2]. This unfortunately continued to happen and S4 left that job.

S5 was driving but there were major concerns about his driving and therefore when he was offered another job by his company which required him to drive long distances to work [3], he did not take it up and this had a major impact on his ability to sustain employment [4].

F6 felt that S6 had no difficulty driving [5]and this was good for his work. But felt that in his current job he did not like the driving to work for financial reasons [1] but this was not reported to have an impact on sustaining employment.

S7 did not drive but initially was driven to work by her husband and picked up afterwards (he gave up his job to do that) till she became confident on the buses

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[1] Document '2S', Paragraphs 176-177, R2, Paragraphs 95-97.
[22] Document '4S', Paragraphs 891-911.
[3] Document '5F, Paragraphs 605-607.
[4] Document '5S', Paragraphs 63-65.
[5] F6, Paragraphs 91-95.

[2]where handling tickets were a problem because of her difficulty understanding heard numbers as she described, *"when I get on the bus. I mean I cannot ask for a return. And I think he said they – I said that right, fare, 2 pound 10 pence. And I've got to say it out – if I'm saying I'm thinking – the way I think, like if somebody said to me, that's 2 pound 10 pence please. Talking to the bus driver. Can I have 2 ..pound ..10 ..pence – and I'm thinking to myself, he's looking at me funny. (laughs) Cos I keep wondering have I got it right or not, you know?"* [3]

S8 did not drive and either his father or girlfriend had to take him in to work and this was a problem especially on the weekends, so much so that the only reason attributed to his poorly sustained employment apart from the difficulty with his line manager was this. He said, *"(how did you get to work and back?) Yeah, that was one of the reasons why I left the job at ****. Because I had to start there at 7 o clock in the morning. Get up for there at 7 o clock in the morning. And I've got a girlfriend who has a car. And I used to get her to give me a lift. Not very fair to girlfriend. Up at 6 o clock every morning to give us a lift to *****."* [4]

Thus travelling to and from work was a factor that affects sustained employment and is especially a problem for non drivers at unsociable hours (evenings and weekends) or if their working hours extend.

Unsociable or prolonged working hours [5]

This was an issue for S2, S4 and S8 but there was no association with sustained employment. The inability to travel was more of an issue than extended working hours for S4. In a subsequent job where S4 sustained employment, he worked prolonged hours but transport issues had been sorted out. Thus unsociable hours are associated with poorly sustained employment if this causes difficulty getting to and from work.

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[1] Document '6S', Paragraphs 236-239.
[2] Document '7R', Paragraphs 215-222.
[3] Document '7SF', Paragraphs 36-43.
[4] Document '8S', Paragraphs 408-415.
[5] Tree node: Unsociable working hours.

Stress for co-workers [1]

S3's manager reported that he caused stress at work and that this had upset the team and the manager and had resulted in him changing to another department [2].
S5's difficulties with his co-workers have been documented previously and this was a great hindrance to sustained employment.

Thus, there were 2 cases where stress on co-workers affected sustained employment.

Returning to work without vocational rehabilitation [3]

While the inclusion criteria was that all interviewees with ABI had gone through vocational rehabilitation before returning to work, S4 and S5 had previous experiences of returning to work without involvement from a vocational programme.

S4 opted out of the programme for a while and attempted a job by himself - this could not be sustained as it was inappropriate to his abilities at that time.
S5 had returned to work after his stroke and had been referred to a vocational rehabilitation programme by his company after this attempt to return to work failed and he could not sustain jobs in any of the places tried by his managers. In retrospect, S5 said that he felt that he should not have gone back but he had felt that since he had gone back to work straight after his heart attack, he could do so after the stroke [4].

Thus, returning to work without vocational rehabilitation was directly associated with poorly sustained employment in 2 cases.

Issues Relating To Employer / Co-Worker

Employers with a personal experience of disability [5]

Concerns were raised by some interviewees with regards to consent and confidentiality issues in 4 cases and in 2 cases the interviews with employers could not be done for this reason. Therefore case by case analysis was not reported in this

[1] Tree node: Stressful for co-workers.
[2] Document '3E', Paragraphs 42-46, 108-115.
[3] Tree node: Returned to work without rehab.
[4] S5, Paragraphs 225-229.
[5] Tree node: Supportive disability savvy employer.

section. In addition, to protect interviewees, references were also not quoted but issues raised were reported without reference to the case.

There were 3 cases where the employers had personal experience of disability following chronic disease (either they themselves or one of their close family). In 2 of these cases, this had an important impact on helping the individual with ABI to sustain employment. In 1 case the experience had been reported by someone else and so no direct association was noted in the data. But all three cases were notable for the extensive support provided to the person with ABI by empathetic employers with a personal experience of disability. This helped these 3 individuals to sustain employment.

Discrimination

There were no reports of discrimination at the work place. One individual with ABI mentioned difficulties getting called for interviews if disability was mentioned on the application form and this was his reason for non disclosure to his employers and also the reason for the researcher not to be able to interview this employer. But there were no reports of discrimination at work even in that case.

Support from employers [1]

Three cases had difficult immediate supervisors but supportive employers had helped the individuals to sustain employment - in fact the supervisor in one case was not able to sustain her employment. One case had a very supportive immediate supervisor and manager and, again, was able to sustain employment.

Another feature of support was through employment policy. Two companies in this series of cases had disability policies. One had a policy advisor and another had won awards for their disability policy and in fact the manager was the local disability champion. Both employees were able to sustain employment and were appreciative of their work places and policies.

[1] Tree nodes: Supportive disability naïve / savvy employer, coping with difficult supervisor.

In two cases when supervisors and employers were difficult, it caused poorly sustained employment but they were able to sustain employment in an environment of support from their employer. Two cases could not sustain employment after disagreements with their previous employers.

Thus, support from employers (not necessarily co-workers) was associated with sustained employment and vice versa.

However, there is a possible negative case: In one case a very supportive company actually referred the individual for vocational rehabilitation but unfortunately this did not result in sustained employment for other reasons. Though the individual felt that it was for lack of support from his employers, there were conflicting opinions from others within the triangulated data of the case study regarding this. Thus, having supportive employers was variably associated with sustained employment.

Self Employment [1]

There was one case (S2) where a self employment model was operative for his summer job. This is mentioned under twinning and gives an example of how it is also possible to sustain a self employed job.

Issues relating to Work Transition

Career Advancement [1]

The issue of career advancement came up in almost all cases. S1 has already been described as having obtained promotions successfully. S2 also started to help in training children to ski. Career advancement was a choice available to S3 though there was no indication that he would choose it.

S4 tried various jobs but it was seen that he was only able to sustain employment at basic levels of work for a multiple set of reasons. Career advancement thus adversely affected sustained employment.

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[1] Tree node: Self employment.

S5 was not thought to be willing to consider a lower level job which would have been more appropriate to his level of ability i.e. career advancement was a hindrance to sustained employment.

S6 did not have options for career advancement.

S7 had options for career advancement but realistically chose not to take them till she felt able to do so. In fact her manager was encouraging her to do so but she was happy at her level.

S8 initially moved quickly up the ladder at work but then was not able to sustain employment for reasons not related to this.

Thus career advancement was not directly associated with sustained employment. There was no pattern of association with outcome. However, inappropriate advancements resulted in poorly sustained employment in one case.

Changing jobs - benefits of a multi department company [2]

S3 and S5 worked for large companies with many departments and branches. Thus when difficulties came up, it was reported that they were moved to other departments. This was in contrast to S4, S6 and S8 who could not sustain employment in similar situations. Thus, there was an advantage in working for a large company but this was not directly associated textually and opposite outcomes were seen in both cases: S3 sustained employment whereas S5 was not able to do so. Thus, this is an indirect and variable association between changing jobs, between moving around in a large company and sustained employment.

Layoffs [3]

This was associated with poorly sustained employment for S4, S5 and S6.

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[1] Tree node: Career advancement.
[2] Tree node: Changing jobs.
[3] Tree node: Layoffs.

THE IMPACT OF A VOCATIONAL PROGRAMME ON SUSTAINED EMPLOYMENT

Follow up [1]

There were several issues raised by interviewees regarding follow up by a vocational rehabilitation programme. The most striking result within follow up issues was that **sustained job coach contact** was associated with sustained employment in S1, S2, S3 and S7 whereas there had been little or no contact after completion of the vocational programme for those who did not sustain employment (S4, S5, S6, S8).

The other major theme in follow up was described by S6's girlfriend who had all but been his job coach over the last two years. She coined the term "opt in" follow up to define the programme's follow up policy of expecting clients to call in if they needed help. In contrast, she suggested an "opt-out" follow up - where the programme actively follows up a client till they are comfortable not to be followed up. This was reflected in all the other cases and was directly associated with sustained employment

S1 had his job coach continue to come and sort issues out with his supervisor at work and he kept in touch with her even after she had left the vocational programme, thus adopting an opt-out pattern for himself which he reported to have helped him sustain employment.

S2, though not in contact with job coach, was supported by the psychologist from the community rehabilitation team who continued to play a troubleshooting role in S2's life and this opt-out follow up pattern was reported to have helped sustain employment.

Similarly, S3's job coach and manager maintained close links as S3 had made several interdepartmental moves and was trying various methods to compensate for his memory difficulties at work.

[1] Tree node: Follow up.

Also S7's job coach continues to play a specific role in helping sort out problems with answering phones. Thus an opt-out pattern of follow up is directly associated with all 4 cases who sustained employment.

On the other hand an opt-in follow up pattern was seen for S4, S5, S6 and S8. They all reported very little to no contact with their job coach. Three of their job coaches had left the vocational rehabilitation programme. There was no expectation of help from these individuals with ABI and it was reported that this had an impact on their ability to sustain employment. While S6's job coach felt that he would call in if required [1], this was not actually the case with S6 who did not feel that he needed to call in to the programme [2]. There had been potentially risky moves by clients which were not followed up by the programme e.g. when S6's planned move into work after training failed because of a lack of job availabilities or when S8 resigned after difficulties with his manager. Therefore opt out follow up associated with sustained employment in all cases and opt in failure associated with poor sustainability of employment in the four other cases.

Thus, sustained follow up is associated with sustained employment. A pattern of opt-out follow up is preferable especially when potentially adverse situations occur.

Roles of a vocational programme

Building confidence [3]

There were several interviewees who reported that the most useful benefit of going through the vocational programme had been a build up of confidence in S1, S2, S3, S4, S7 and S8. However S5 and S6 were reported to be overconfident and this was not an issue. Also confidence was not an issue in the poorly sustained employment of S4 and S8. Thus, building confidence is both directly and indirectly associated with sustained employment.

[1] Document R6, Paragraph 244.
[2] Document S6, Paragraph 60.
[3] Tree node: gaining confidence.

Helping learn limitations

S1 was "committed from the onset to face up to his demons and overcome his deficits and very open to a range of cognitive strategies" [1] and it was felt that without the vocational programme he would never have returned to work [2].

S2's parents said that the vocational programme came in just at the right moment when they had realized that they had gone as far as they could go and the programme had introduced some good things to S2 which had helped. However there was no specific reference to sustained employment. In fact S2 had not maintained some of the things he had learnt.

S3 was helped by getting him into the habit of writing and even laminating his rotas. This continued and helped him to be at work regularly.

It was felt that S4 was supported too much by the programme which was in its infancy at that stage and that this had meant that S4 did not realize his limitations resulting in poorly sustained employment [3].

S5 realized the impact of his fatigue only after getting into the vocational programme[4]

Similarly S6 was helped to identify many things that he had assumed were alright [5].

S7 was helped and advised to choose a suitable placement and S8 felt he benefited from the cognitive exercises.

Thus, even though this was not associated with sustained employment, all individuals with ABI were helped to learn their limitations by the vocational rehabilitation programme.

Similar pictures emerged for other roles played by the vocational programme - choosing skills to develop, peer interaction and introducing structure. These were all appreciated but no direct link to sustained employment was evident.

Support for carers of individuals with ABI was another role mentioned but this was not associated with sustained employment either.

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[1] Document R1, Paragraphs 67-70.
[2] Document F1, Paragraphs 679.
[3] Document R4, Paragraphs 290-299.
[4] Document S5, Paragraphs 1005-1011.
[5] Document S6, Paragraph 619.

Placements

Placements which were categorised as appropriate and interesting (S1, S3, S7 and S8) all resulted in sustained employment. Even though S8 did not sustain employment, this was related to a change in job requirements and supervisor. In some cases (S1, S4 and S6) inappropriate but interesting placements, though successfully converted to employment, did not subsequently continue on to sustain employment. In fact with S5, such placements had an adverse effect though with S3 and S4 these were not reported to have made any effect. Appropriate but uninteresting placements for S3 and S4 were neither associated with return to work nor sustained employment. However such a placement for S2, despite being something he hated (gardening) has resulted in sustained employment in the summer.

Admission to the vocational programme was based on criteria which were relaxed for S1 who had pre-injury alcohol difficulties and for S5 who continued to have difficulties with alcohol. These two cases represent the two extremes and so there is a variable association with relaxing admission criteria to such a programme. In addition there were no cases where the individual self referred to the programme - there was always a referrer who facilitated the referral. However this was not directly associated with sustained employment. Finally an issue raised by the staff of the programme was that in its infancy, or when a new staff joined, there were things that would have been done differently with the benefit of experience and hindsight - this was raised in S4, S5 and S6's cases.

OTHER ISSUES NOT DIRECTLY ASSOCIATED WITH SUSTAINING EMPLOYMENT

Issues not related to ABI

S4 could not sustain employment on two occasions for reasons of poor health (not related to ABI).

The impact of physical sequelae after ABI [1]

Several issues were raised in the area of physical sequelae after ABI. These were relating to how the ABI occurred and what was done about it as well as medication or surgical intervention. Other issues raised were their age, independence and visual difficulties and ability to drive - but none of these had impact on their employment.

S1 had a very tumultuous period after his ABI but recovered physically. He was confused and could not remember his family initially. He tended to wander. But in a year 's time he had recovered sufficiently to be able to drive again. He continued to take Phenytoin for seizure prevention but this did not affect work. He never got back his sense of smell and always worried about gas leaks at home. Occasionally he noticed a little difficulty on his right side.

S2's physical ability was very good. His speech was slurred and he had a residual strabismus (squint) which resulted in people thinking he was drunk. However there was no difficulty with his driving.

S3's parents were not given much hope of S3's survival after the accident but over the months he slowly recovered. He had a violent temper and refused to be groomed initially. But over time he became independent. He remembers being frustrated at not being able to speak initially.

S4 did not have any residual physical sequelae but had frequent shunt blocks. His visual field deficit meant that he could not return to driving. He slowly learnt to compensate for the deficit and stopped bumping into things and missing things out when he was reading.

Though S5 was physically able and independent, over time he has stopped looking after himself. He was on Aspirin and Sotalol for several years (after the heart attack).

[1] Integrated memo: IM after – Physical.

S6 had problems with pain and heterotopic ossification after ABI. This meant some restriction of lower limb joints requiring surgery but not restricting his function in any way.

S7 and S8 took some months to recover physically but do not report any physical problems now.

Thus, though several issues with physical abilities were raised, none had an impact on sustained employment.

The impact of social issues [1]

S1, S2, S3, S4 and S5 had to change house after the ABI but this was not reported to affect sustained employment.

S1 and S2 had supportive friends and neighbours. S3 and S8's friends all went their ways to university or jobs. S7 and her husband found that some of their friends stopped visiting them after the stroke. But none of this had any impact on sustained employment.

S1 was helped by social services and GNER supported him with a railway pass to travel to work in the initial month of paid employment. S3 did not have social services support and S6 came off allowance and his income was protected for a year through social services support. S7 felt abandoned by social services. S8 was supported by a compensation package. None of these were reported to influence sustained employment.

S2 was vulnerable to customers who realized that he was different and that they would "*get away with things with S2 that they wouldn't with other staff*" [2]. S3's father feared that S3 would be "*left too much to his own devices*" [3] and would be vulnerable to friends who took advantage as had happened once before. S4 was considered too

[1] Integrated memo: IM after – Social.
[2] Document E2, Paragraphs 82, 83.
[3] Document F6, Paragraph 544.

trusting and therefore vulnerable. But again these fears of discrimination or exploitation did not actually affect sustained employment.

S4 had cultural and language differences but these did not impact on employment.

Thus, none of the issues around social function affected sustained employment.

The impact of family after ABI [1]

There were several appearances of family support in the data but none in context of employment. All cases except S4 were supported by family. S4 was separated from family and this process caused depression which in turn affected sustained employment but there was no direct link. S5 was also divorced but then he was supported by his parents. His daughter arranged for one of his placements. S7's husband helped her by taking her to and from work in the beginning.

Overall, 2 of 4 cases who had poorly sustained employment had gone through divorce after ABI. The other 2 were still supported by partner or parents. Whereas all four who had sustained employment had family support. However family support after ABI was not reported to directly impact on employment or work quality.

The impact of financial issues [2]

There were several reports of individuals with ABI being careful with their money and spending - S1, S2 and S5. S4 and S6 initially needed help to organize their accounts. S3 was a liberal spender and there were disagreements with his father about his handling of money. But these were not reported to affect sustained employment.

There were 2 instances of financial issues working as incentives: S3's company received incentive for employing him and S7 was motivated to work by their financial need. However there was no direct association to sustained employment.

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[1] Integrated memo: IM – Family.
[2] Integrated memo: IM after – Financial.

Also, S6 and S7 were helped by government incentive schemes to supplement their income and protect their allowance respectively in the initial stages of return to work. While this helped them to get jobs, none of these affected sustained employment. Though S6 was hesitant about losing allowance after a bad experience, he felt that he "*was sick of sitting there and doing nought*" [1].

There were instances of financial disincentives after return to work - S1's father said he was financially punished for trying to start to work [2], S3's father estimated that he was losing £65 a week because he works more than 12 hours a week [3]. Both sustained employment and these facts appeared to be unconnected to each other.

There were 2 instances (S2, S8) of compensation money being sufficient to provide regular income and therefore being potential disincentives. But S2 continued to work and said he was earning "*love money*" - earned from the love of skiing, not for the love of money [4]. S8 felt "*he ought to be doing something*" [5] and also continued to work though he later stopped for reasons not connected to this. His father felt that the compensation money was a reason for him to be slow in looking for another job, but S8 was in the process of job seeking.

S4 also preferred work despite disincentive in the form of allowances and said " *it wasn't enjoyable because I wasn't working for it. Now I work for it and I can do what I like with the money, its mine.*" [6].

S5 vacillated between saying he wanted to work and that he would only work if he got more than his insurance package: "*I've got no incentive to go back for another employer. Lose everything and finished – which is silly really. But that doesn't mean to say that I don't want to actually physically work.*" [7] and "*Obviously I wouldn't*

[1] Document S6, Paragraph 282.
[2] Document R4, Paragraph 303.
[3] Document F3, Paragraphs 386-394.
[4] Document S2, Paragraph 185.
[5] Document S8, Paragraph 378.
[6] Document E4, Paragraphs 846-848.
[7] Document S5, Paragraphs 114-117.

want to go back on lesser money than what I was getting on insurance because that would be a bit silly, but I would rather be working than not working." [1]

Thus, there was no direct textual link between financial themes and sustained employment. However financial incentives occurred in 3 events of sustained employment. Financial disincentives were overcome in 2 events of sustained employment and not overcome in 3 events of poorly sustained employment (indirect association).

SUMMARY

Personality and behaviour

1. There were personality changes reported after ABI - either losses or exaggerations and in one case, a return to pre-adult personality.

2. Those who sustained employment had unconditional motivation to return to work. Those who did not sustain employment were noted to have placed conditions on their motivation. A sense of responsibility and overcoming a sense of victimization was noted among some who sustained and did not sustain employment.

3. Passivity was seen as affecting sustained employment in 3 cases.

4. Friendliness helped sustain employment in 3 cases and helped work quality in 2 cases.

[1] Document S5, Paragraphs 105-107.

5. Poor anger management was seen in 2 cases of poorly sustained employment. However there were 3 cases where though this was a problem it was not reported to have affected employment.

6. Inflexibility affected sustained employment in one case, affected work quality in one case but did not have an impact on work in 3 cases.

7. Being oversensitive, over confident and inappropriate occasionally affected quality of work but these did not affect sustained employment. Intolerance and impulsivity were reported in 1 and 2 cases respectively but this was not described in the context of work. Similarly a sense of humour came up in 2 cases but not in the context of work.

Cognitive function

The presence of the following cognitive features helped to sustain employment:

- Using external aids for short term memory difficulties.
- Acting on insightful recognition of cognitive difficulties.
- New learning ability.
- Compensating for mental fatigue (reduced hours, breaks).

The following were variably linked to sustained employment (sometimes harmful, sometimes not):

- Poor attention and concentration.
- Confabulation.
- Poor organization and planning.

Slow processing speed, Perseveration, Poor multi-tasking ability and visuospatial difficulties affected work quality but not sustained employment. Good multi-tasking ability and memory did not necessarily help sustain employment.

Long term memory and difficulties in reading, writing and speaking were neither reported to affect work quality nor sustained employment.

Psychiatric function

1. Paranoid feelings affected sustained employment in a situation in one case where the individual with ABI acted on those thoughts. However, in another case, when acting on feelings of paranoia was suppressed, it did not have an impact on work or sustained employment.

2. Depression affected sustained employment in one case.

3. Intolerance to alcohol did not affect sustained employment in all the case studies, though it did affect work quality in one case. However it was sorted out when consumption at work was controlled by the employer.

Work interests and skills

1. There was a variable association between enjoying employment and sustaining it.

2. Good coping skills were associated with sustained employment and vice versa.

3. Time keeping. Grooming and work training courses were not associated with sustained employment.

Work environment issues:

1. Having a co-worker alongside (Twinning) at work was associated with sustained employment in 4 cases (S2, S3, S6 and S8).

2. Being an outstanding employee at work was associated with sustained employment for S1 and S2.

3. Problems with getting to and from work were directly associated with sustained employment especially for non-drivers who had to work unsociable hours.

4. In the 2 cases (S3, S5) who caused stress to co-workers, this impacted sustained employment though in S3's case this resulted in an interdepartmental transfer rather than a loss of employment.

5. In the 2 cases (S4, S5) who returned to work without vocational rehabilitation, this directly affected sustained employment.

6. Unsociable working hours (S2, S4, S8) affected work quality in 3 cases but there was no impact on sustained employment.

Employer / Co-worker (some summary points made anonymous)

1. Having an employer with a personal experience of disability was associated with sustained employment in 3 cases.

2. Having a supportive employer or disability work policy was associated with sustained employment and vice versa. However there was one case where despite extensive support, this did not result in sustained employment.

3. There was one successful self employment model in the data.

4. Discrimination was not raised as an issue for sustained employment.

Work Transition

1. Career advancement was variably associated with sustained employment.

2. Changing jobs within a large company were variable associated with sustained employment.

3. Layoffs were associated with poorly sustained employment.

Vocational rehabilitation programme

1. Sustained job coach contact is associated with sustained employment in all cases. All those whose employment was poorly sustained did not have sustained contact with their job coach.

2. Opt- out follow pattern was associated with sustained employment in all 4 cases whereas failed opt-in follow up was related to poorly sustained employment in 4 cases. The opt in follow up pattern especially failed to pick up adverse circumstances.

3. Appropriate, interesting placements resulted in sustained employment.

Vocational programmes helped build confidence and learn limitations which helped improve work quality but did not have an impact on sustained employment.

Others

1. General health issues were associated with poorly sustained employment.

2. Several issues relating to physical ability after ABI were raised but were not associated with sustained employment.

3. A few issues of social support were raised but none were associated with sustained employment.

4. Though all cases of sustained employment had good family support, this was also noted in 2 of the 4 cases of poorly sustained employment and there were no direct associations noted in any of them. In the remaining 2 cases, there was no direct association between poor family support and sustained employment. Thus, there is no direct association of family support with sustained employment nor an indirect association.

5. Overcoming financial disincentives and receiving financial incentives were indirectly associated with sustained employment.

Chapter 7

A CONCEPTUAL MODEL

If (God smiles) on you, your study will have moments when things fall in place.
Colin Robson (tense changed)(Robson 2002)

This chapter discusses the development of the conceptual model of sustained employment in ABI. A model is an overall framework for looking at reality. A concept is an idea deriving from a model (Silverman 2001). This chapter outlines and discusses the ideas emerging from the results of this study. The overall framework of these ideas or concepts is then described in a conceptual model.

CONCEPTS OF SUSTAINED EMPLOYMENT

There were several factors which emerged in this study which were **directly associated** with sustained employment i.e. there were direct textual references linking the factor to employment outcome. These factors gave rise to ideas or concepts of what helped to sustain employment or what adversely affected sustainability.

The concepts in sustained employment fit into the framework suggested by the International Classification of Functioning, Disability and Health (ICF). The ICF challenges the well known ICIDH triad of impairment, activity and participation. The ICF proposes that social and environmental factors affect impairment, activity and participation. These ICF domains fit into the ICIDH triad in a bio-psycho-social framework (WHO 2001). The concepts based on factors which were directly associated with sustained employment were bio-psychological (relating biological and psychological function), and social (internal and external social influences). These are listed in Table 7.1.

Table 7.1:Factors directly associated with sustained employment

What helped to sustain employment?	What adversely affected sustained employment?
Bio-psychological concepts *Motivation and Coping skills* ▪ Unconditional motivation ▪ Use of coping strategies for cognitive difficulties and fatigue ▪ Coping with mental fatigue Pre-injury issues ▪ Previous leisure interest ▪ Previous work skills and interest ▪ Recognizing and coping with adverse pre-injury personality traits	**Bio-psychological concepts** *Motivation and Coping skills* ▪ Conditional motivation ▪ Passivity and lack of drive ▪ Poor awareness or coping skills ▪ Not coping with mental fatigue ▪ Not acting on insight ▪ Not coping with confabulatory memory ▪ Not compensating for poor organization ▪ Not coping with Anger ▪ Not coping with Paranoia
Social concepts *Work environment* ▪ Supportive employer – especially those with previous experience of disability – Changing jobs in a large company ▪ Supportive co-worker: Twinning ▪ Being an outstanding employee *Vocational rehabilitation programme support* ▪ Building confidence ▪ 'Opt –out' follow up ▪ An appropriate, interesting placement	**Social concepts** *Work environment* ▪ Stress among co-workers ▪ *Layoffs* ▪ *Difficulty travelling to and from work* ▪ Unwilling to change jobs in a large company ▪ Poor health not related to ABI *Vocational rehabilitation programme issues* ▪ Return to work without vocational rehabilitation ▪ Opt-in follow up

Bio-psychological concepts

The three key bio- psychological concepts of sustained employment that emerge from the results are:

- Coping skills supersede basic cognitive, executive, behavioural, personality and metacognitive factors and helps to sustain employment even when these other factors are severely affected.
- Unconditional motivation to work helps to sustain employment.
- Pre-injury leisure and work interests have a major impact on sustaining employment and can help a person's motivation and coping skills.

These are discussed below.

Coping skills

Coping has been defined as "the constantly changing cognitive and behavioural efforts to manage the internal and external demands of transactions that tax or exceed a person's resources" (Folkman, Lazarus et al. 1986).

Coping difficulties have been noted in unemployed people. One type of coping style seen in the unemployed is *emotion focussed coping* which includes relaxation, exercise, seeking emotional support and social support, self blame, wishful thinking and avoiding thinking of the stressor (psychological distancing). The other observed coping style among unemployed people is *problem focussed coping* which includes job seeking, re-training, relocation, cognitive re-structuring and controlling non-work life activities like saving money or staying active. Problem focussed coping styles have sometimes been associated with re-employment (Grossi 1999).

Coping has been described as an important mechanism in traumatic brain injury. But the severity of injury has not been associated with maladaptive coping skills (Huey 1997).

This study list highlights the importance of coping strategies in ABI and a review of the list above shows its over-arching influence on basic cognitive and executive function, personality traits, emotions, skills and even psychiatric difficulties. The

presence or absence of coping defines whether the particular factor is associated with sustained employment or poorly sustained employment, thus categorising it as a "super-skill". Several examples are seen in this study:

Tiredness has been reported to have an impact on employment (Lock, Jordan *et al.* 2005). This study reports that this tiredness is a 'mental fatigue' (more than a physical fatigue seen in other neurological conditions). Interestingly, rather than the fatigue itself, it is the ability to *cope* with this fatigue which helps sustain employment. This can be done either by taking frequent rest periods or by breaking down cognitively challenging tasks into smaller portions e.g. an individual who recognized that tiredness and lack of concentration were causing a lot of difficulty at work but did not use strategies to cope with this and was unable to sustain employment despite having a supportive employer.

Coping skills have helped to overcome basic cognitive disability and helped to sustain employment. Among several examples was the example of an individual with difficulty understanding numbers who has successfully managed a numerical database at work by writing things down. This individual was supported at the work place by being allowed not to use a phone at work.

These findings also demonstrate the importance of coping skills in Metacognition, or a person's awareness and control of cognitive functions and abilities. When insight or awareness of difficulties was present and when the individual used this awareness to actively take steps to cope with those difficulties, it helped to sustain employment. Those with insight who did not follow through with coping skills were unable to sustain employment.

Cognitive and executive difficulties by themselves did not seem to be associated with poorly sustained employment. Indeed, individuals with fairly severe cognitive difficulties sustained employment by using coping strategies. But if coping strategies were not put in place, then cognitive and executive dysfunction was associated with poorly sustained employment. This concurs with previous research which did not find a consistent relationship between neuropsychological function and employment outcomes. Also there was little evidence to support "direct attempts to remediate

neuropsychological function beyond the natural recovery phase" (Carney, Chesnut *et al.* 1999). Thus the fact that there is something beyond basic and executive cognitive function which has an impact on employment outcome is apparent. This research suggests that this is the ability to use coping strategies.

Motivation

Motivation comes from the Latin "movere", which is to move. It is the general term for "all the processes involved in starting, directing and maintaining physical and psychological activities". Motivation embraces a host of internal mechanisms such as preference for one activity over the other, preferential vigour or strength of response and persistence of organised patterns of action toward relevant goals. Thus a motivated person seeks out certain activities over others, practises behaviours and perfects skills required to attain the objective; and focuses energy on reaching the goal despite frustrations (Zimbardo, McDermott *et al.* 1995).

Though there is no taxonomy of motives that is accepted by a majority of psychologists but 3 motivational systems have been suggested: Biological, Social and Cognitive motivation.

Biological motivation refers to drives to meet physiological needs and may be instinctual. Social and Cognitive motivation, "rather than directed at specific goals like drives, have a more general goal of adapting the individual to the environment". Social motivation helps individuals adapt to their environment by developing into a system of "belonging-ness" because wanting to belong is considered to be a basic need (Buck 1988; Koestner and McClelland 1992). Cognitive motivation helps adapt to environment by developing into a system of meaning. This intrinsic motivation is explained by "expectancy value" theories which say that previous reinforced learning experiences make us expectant and willing to learn. Another explanation is that we are energised by "effectance" or the joy of discovering cause and effect. Thus often, work is carried out without a purpose beyond the immediate reward of doing it (White 1959; Zimbardo, McDermott *et al.* 1995).

This study also highlighted the importance of motivation in sustaining employment. There were two types of motivation noticed:

1. "Unconditional motivation" was described as the motivation of individuals with ABI to work, "come what may". This was shown to help to sustain employment.
2. In contrast, "Conditional' motivation" was described if their desire to work was subject to a set of conditions. Conditional motivation was associated with poorly sustained employment.

Like coping strategies, motivation tended to supersede ability. There were instances of motivation increasing the residual potential of the individual beyond those expected by family and vocational programme. Thus motivation is an important factor in sustaining employment.

Pre-injury factors

In previous research, there was a variable association between pre-injury personality and stable employment (Fraser, Dikmen *et al.* 1988). In this study, several pre-injury issues were directly associated with sustained employment. Some of these were related to coping skills referred to above (modifying adverse pre-injury personality traits). Some were related to retained pre-injury characteristics like friendliness, management skills and new-learning skills.

Previous research showed a variable association between return to pre-injury work positions and employment (Ownsworth and McKenna 2004). This study shows a more specific benefit of returning to a job which holds the individual's familiarity and interest: An individual's pre-injury work interest and what he was familiar with helps to sustain employment. In contrast, interest in a post injury job was not consistently associated with sustained employment. Pre-injury work and leisure interests played a major role in motivating individuals with ABI to sustain employment. They also helped to cope with disabilities, some times by using retained skills and at other times by developing them. Thus, this study points out factors within the individual which are waiting to be re-discovered and can be used to help sustain employment.

Some specific interventions for bio-psychological factors were suggested in previous research such as cognitive behavioural therapy, self-awareness training and motivational interviewing, though these have not been fully evaluated (Ownsworth

and McKenna 2004). This study suggests that pre-injury factors can be used to intervene to improve sustained employment.

Social concepts of sustained employment

The major concept in the arena of social factors is the concept of support. This is a theme which runs through previous research on return to work. In the chapter reviewing literature (chapter 2) there are several references to the success of supported employment programmes in the process of return to work. This theme continues into the long term process of sustaining employment and the specific nature of support is discussed below.

Support in the work place

Support in the work place was a major factor which helped to sustain employment. Some of this is reflected in previous research and an especially poignant call for more supportive workplaces was documented in a recent report from focus groups of 'Different Strokes' which is an organization of individuals with stroke in the UK (Lock, Jordan *et al.* 2005). The contribution of this study to existing knowledge is in describing and conceptualizing Rehab UK's specific, constructive ways of providing support in the work place. The particular new and positive highlight was that support given by an employer with a personal experience of disability was directly associated with sustained employment. A negative issue which was highlighted was the individual with ABI causing stress among co-workers thus affecting their ability to be supported in the work place through twinning – the sharing of responsibility or a work role with a supportive co-worker.

Support from the vocational rehabilitation programme and "opt-out" follow up

The primary role of Rehab UK's vocational rehabilitation programme was supportive – it was seen as building confidence in the individual with ABI.

Also, its role in providing support was highlighted in the contrasting nature of two follow-up patterns. Termination of rehabilitation when there is only a minimal functional improvement has been reported to have a bearing on employment (Lock, Jordan *et al.* 2005).

This research echoes similar sentiments and suggests a constructive proposition. The successful "opt-out" pattern was coined by a participant who described the follow up as continuing till the individual with ABI opted out. This was contrasted to the failure of the 'opt-in' follow up. In the less effective opt-in follow up pattern, staff of the vocational rehabilitation programme waited for the individual with ABI to call for help or advice.

Thus, several new biopsychosocial concepts in sustained employment have emerged from this research.

Indirect or absent associations with sustained employment

There were several other factors which were not directly associated with sustained employment and the impact of these factors are discussed in the section below as their absence in the conceptual model represents a paradigm shift from previous conceptual models of return to work.

A few factors were **indirectly associated** with sustained employment i.e. though there were no textual references linking themes to employment outcome, there was a pattern relating themes to outcomes in the interview e.g. the theme occurred in all cases of sustained employment.

There were also factors which were **not associated** to sustained employment and some factors mentioned in previous research were absent from this data.

Factors which were indirectly associated or not associated with sustained employment were not included in the development of the conceptual model as previous research

has reported that "*although the presence of specific characteristics for each factor may be a good predictor of the failure to return to work, the absence of such characteristics does not guarantee return to work*" (Brooks, McKinlay *et al.* 1987). Only factors with direct textual links to sustained employment were used to develop the conceptual model and challenge existing practice.

Some of the indirect or absent associations raise questions about possible drawbacks in the study and these are discussed below in terms of possible bias, selection criteria and the possibility of the lack of representative-ness of the sample.

There were several factors which were surprising in their indirect or absent associations with sustained employment:

1. Difficult financial issues were not associated with poorly sustained employment. Though there were a few examples of individuals overcoming financial disincentives and returning to work, there were no direct associations with sustained employment. However there was evidence that motivation to return to work was stronger than the loss of income resulting from doing so.
2. The presence or the lack of family support was variably associated with sustained employment. Surprisingly, even though family members were interviewed, there were no direct associations between family support and sustained employment, though there were several instances of family helping out in the work situation, these were not described as having an impact on sustained employment.
3. Issues relating to alcohol and substance abuse were not associated with sustained employment and this could be attributed to the fact that only those who are not actively abusing alcohol can enter this and most vocational rehabilitation programmes. Thus, though this was not an exclusion criteria for participation in research, this was a pre-existing exclusion criteria and therefore these issues are unlikely to emerge in this study.

Other factors which were not associated with sustaining employment had either been inconclusively related or not related to return to work in previous research:

1. This study did not find associations in areas such as physical factors, age, severity and type of brain injury, functional status at discharge and

neuropsychological factors. This agrees with previous research which reported mixed findings for these factors (Ownsworth and McKenna 2004) and pre-injury personality traits as well (Rush, Malec *et al.* 2004). On the other hand, this study reported indirect associations for several factors which were associated (though inconclusively) with return to work in previous research. These were:

> Pre-injury education, pre-injury work ethic ("moving on"), helping clients learn their limitations, depression, inappropriate, intolerant or impulsive behaviour, being oversensitive or overconfident, short and long term memory, confabulation, numerical dyslexia, perseveration, processing speed, visuospatial skills, multitasking, time keeping, working unsociable hours, work related training, career advancement, litigation, inappropriate or uninteresting placement or job and relative inexperience of vocational rehabilitation staff.

In retrospect, it is probable that previous research was inconclusive because the association between ABI and vocation lay in a different set of variables than those chosen to be researched. Thus, these indirect or absent associations suggest that further research needs to move away from previously researched factors and develop a new focus for others.

2. Gender issues were not raised in the study. This is not dissimilar to previous research. There was only one woman with ABI in the study. Even though this might be considered a skewed gender distribution, it is representative of both ABI and strokes and the fact that more men sustain ABI than women is referred to in the chapter reviewing literature (chapter 2). However, as a little less than half of all the interviewees were women, opportunity has been given to explore gender based issues. The semi-structured nature of the interview gave opportunity for specific issues and perceptions to be discussed.
3. Job tenure was not raised as an issue in the study and the possibility of bias was considered. It was felt that the researcher and rehabilitation staff were used to long term employment and that this would mean that their perspectives were different from those who were used to 'moving on'. However there appeared to be a similar distribution among the interviewees. Many came from a background of working for several years in one type of job or a single company. However, even though the follow up period in this study was

between 3-13 years after ABI, there was a limitation that the period of follow up after return to work in this study was only 1-3 years.

4. Race related issues which were raised in previous studies did not emerge in this study because the population under study including all the interviewees were racially homogeneous. Similarly functional status at discharge, absenteeism, criminality, discrimination and socioeconomic state could not be explored as the population under study did not report difficulties with these issues.
5. Several issues that were considered to be part of the general environment of unemployment and not specifically related to ABI were not associated in this study. A DWP report (DWP 2002) said that sick or disabled clients were more likely to be in work of at least 16 hours a week if they had a partner, a degree or NVQs, a driving licence, access to a car and a telephone. They were less likely to be in work if they had any dependent children or a child under five, were tenants rather than homeowners, had problems with basic literacy or numeracy and had a private pension from an earlier employment. With the exception of having dependent children below the age of 5, all the characteristics of the general population approaching DWP employment services have been represented in this study. This implies that some of the characteristics seen in this study are related to unemployment (or return to work) rather than specifically related to ABI sequelae.
6. Cognitive issues were not associated with sustained employment in this study. The possibility of missing an association because of the absence of formal testing of cognitive function was considered. The ACE was used to provide a baseline measure to interpret the interviews with individuals with ABI. Other quantitative tests were not included at the design stage as these had not shown much promise in previous research (Crepeau and Scherzer 1993). However, the study would have picked up the functional issues of cognitive dysfunction in relationship to work. The vocational programme itself had used some formal neuropsychological testing but vocational rehabilitation staff felt that these were of limited use in the vocational process. So it was unlikely that the lack of formal testing resulted in this finding.
7. There were 2 employers and 1 family member who could not be interviewed and this might have caused a "triangulatory hole". However, though their

perspectives were not obtained, there was only 1 drop-out in each case i.e. triangulatory evidence was obtained from three other interviewees in every case of drop out. Also, respondent validation confirmed the accuracy of the process of data collection and transcription.

Thus, it is unlikely that methodological issues, bias or lack or representative-ness could account for indirect or absent associations with sustained employment. Therefore some factors which were proposed in previous conceptual models of return to work could not be included in the conceptual model that is being proposed in this study.

Which factors are relevant in sustaining employment?

It has been thought that the challenges facing activity and participation in a person with ABI comprises of physical, cognitive and psychiatric or neuropsychological disability causing organic personality or emotional disorders and resulting in impairment in function (Whyte, Hart *et al.* 1998; Miller, Burnett *et al.* 2003; RCP-BSRM 2003). The results from this study indicate that a person with ABI appears to face a different set of challenges to activity and participation.

Data from this research suggests that vocational rehabilitation needs a much greater emphasis on *bio-psychological* concepts. This includes:

- assessment of pre-injury work and leisure interests and their potential impact on motivation.
- assessing and developing coping skills for cognitive, psychiatric and behavioural sequelae of ABI.

The *social* concepts of work support indicate that there is a need to:

- identify empathetic employers
- identify co-workers who are willing to be twins
- assess co-worker stress

In addition the vocational rehabilitation programme should:

- Facilitate confidence building and
- Follow an opt-out follow up pattern.

Physical, cognitive, social, educational, financial and family factors are indirectly associated or not associated with sustained employment.

This suggests a paradigm shift in the understanding of the vocational process. The implications of these biopsychosocial concepts fitted into the ICF framework are discussed in the next section.

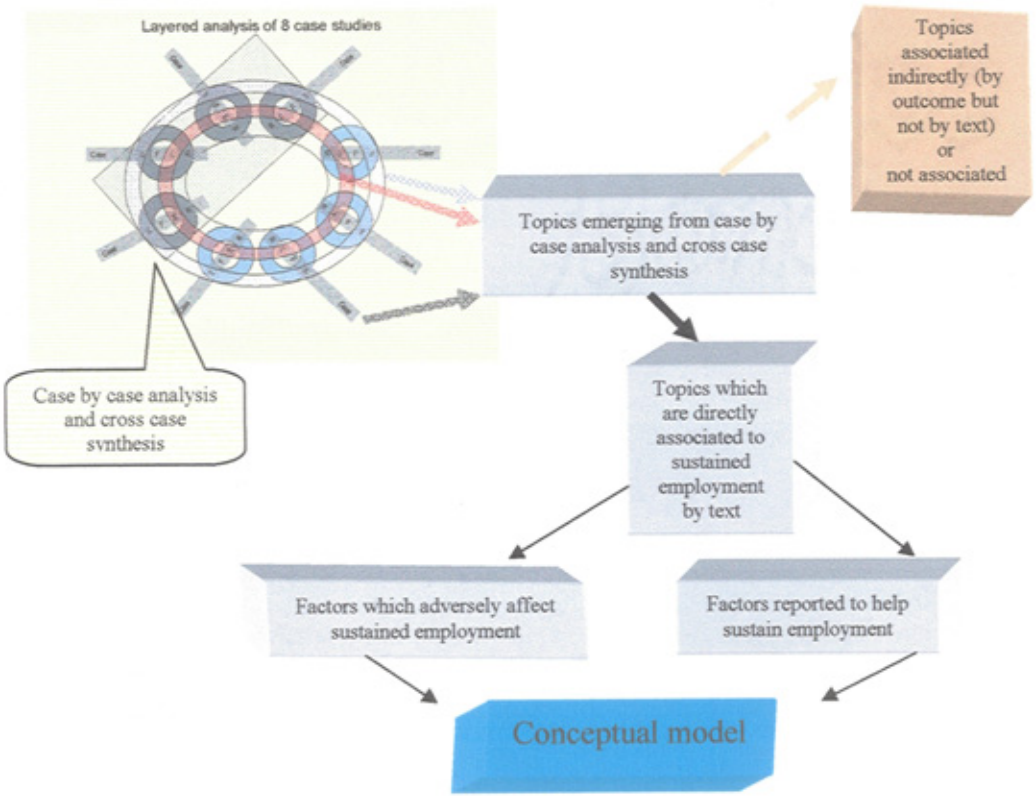
A CONCEPTUAL MODEL OF SUSTAINING EMPLOYMENT

A conceptual model is constructed from concepts which are placed in a framework in order to understand or describe reality. This occurs in an attempt to "think from exemplars". Thinking from exemplars is a process of reflection where similarities in known processes and their solutions, help researchers to understand a new process. This thinking process results in the development of a "generative metaphor" or a picture of such a comparison which generates a conceptual understanding of the problem and then informs the process (Schon 1991). The conceptual model of sustaining employment constructed below takes a known understanding of cyclical phenomena like physiological feedback loops or alternatively, the design of automobile gears and applies this to the process of sustaining employment. In the next chapter, the implications of this generative metaphor on practice are described.

The process of construction

The conceptual model is defined as a framework which outlines the major factors involved in a process and explains the relationship between these factors. These factors were used to develop the conceptual model as shown in Figure 7.1.

Figure 7.1: How the conceptual model was developed



There were 2 conceptual models proposed for vocational rehabilitation in previous research (Vandiver, Johnson *et al.* 2003; Ownsworth and McKenna 2004) which were outlined in Figures 2.3.and 2.4 (on pages 53,54) and suggested:

1. A linear model of entry and exit of the vocational process
2. Step-wise serial stages for medical and social model activities
3. All ABI sequelae, including unproven or insignificant variables, were included in the model with equal emphasis.
4. Only broad thematic categories were outlined at each stage and specific details were not included.
5. The end-point was return to work, not sustaining employment.

This study proposes changes which are difficult to incorporate in the previous models and therefore a new conceptual model is proposed in which:

1. The bio-psychological and social concepts are integrated (biopsychosocial model) right from the placement onwards to help sustain employment. Examples of this integration were demonstrated in the study when employers helped sustain employment by implementing work strategies to cope with the individuals' cognitive difficulties.
2. The model is relevant to the emerging concepts. Thus biopsychosocial concepts which were elaborated in the first section of this chapter are included in the model while those factors which are not directly associated are excluded.
3. Specific useful interactions between factors are included e.g. there were appropriate interactions between pre-injury work and leisure interests and motivation and this needed to be included in the model.
4. The opt-out follow up pattern was represented in the model. i.e. continued involvement unless the individual with ABI decides otherwise. To include this, the process is parallel and cyclical rather than linear and step-wise. The importance of continuous follow up to provide feedback to the process in a physiological manner is the best representation of the process of sustaining employment which was observed in this study.

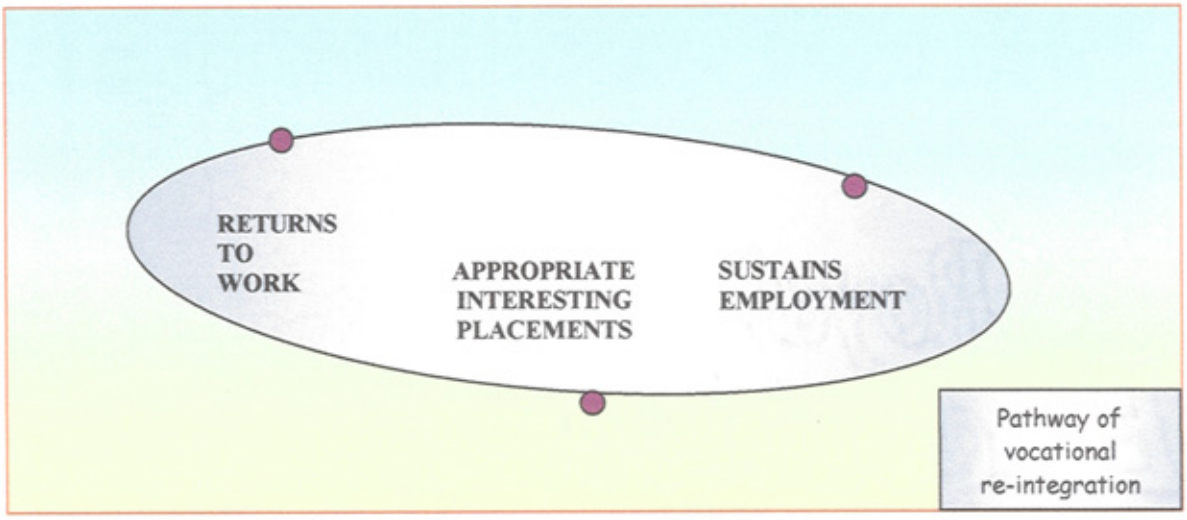
Building the conceptual model of sustained employment in ABI

The actual construction of the conceptual model based on the above requirements is outlined in 4 steps below.

Step 1: Pathway of the vocational process

The first step is to build a pathway to represent the vocational process. This vocational process starts when the individual with ABI enters a vocational rehabilitation programme and as described previously undergoes modules including placements, return to work and sustaining employment. If employment is poorly sustained (as occurs in around half of those who return to work), then the process of placements and job seeking will need to be re-visited. Therefore this pathway needs to be cyclical as seen in Figure 7.2.

Figure 7.2: Construction of the pathway representing the vocational process: step 1



Step 2: Interaction with Bio-psychological framework

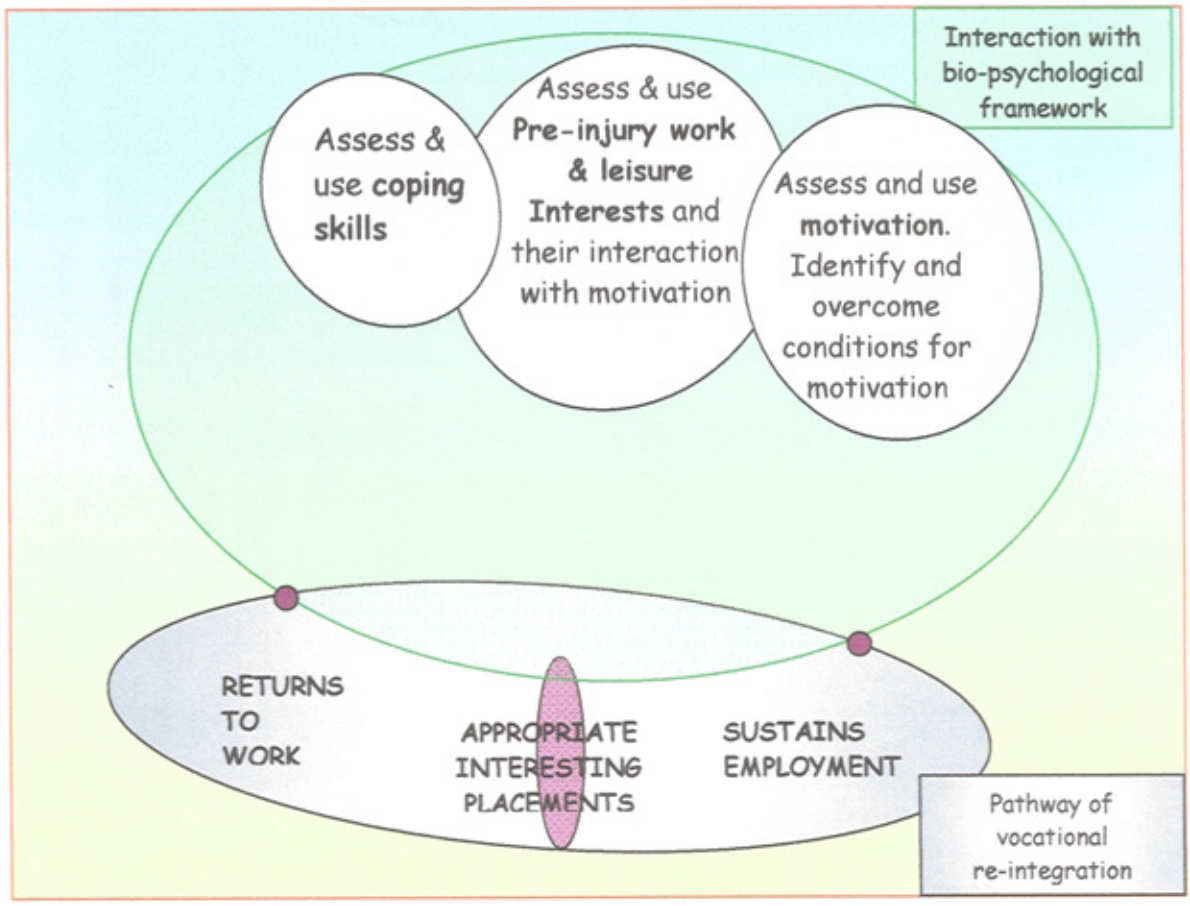
The three main bio-psychological concepts and their interactions with each other and the vocational process need to be included in this part of the framework. The main requirements are:

1. To emphasise that coping is a "super-skill" which can influence cognitive, behavioural, psychiatric and personality characteristics (however severe). Putting this concept into practice will include identification and use of coping skills in all these areas.
2. To emphasise that pre-injury characteristics such as work and leisure interests are important. Again the identification and use of interests should be represented in the framework.
3. To emphasise that unconditional motivation is important and can be influenced by pre-injury interests. Practice of this will include identifying the conditions operating on a person's motivation, exploration and use of the pre-injury interests on motivation
4. That the practice of these 3 concepts should be available to every stage of the vocational pathway at any point in time

If these hierarchies and interactions need to be represented in a framework, the simplest diagram would be one of overlapping cycles which interact to offer any

permutation and combination of choices throughout the vocational pathway. This is shown in Figure 7.3:

Figure 7.3: Interaction with bio-psychological framework: step 2



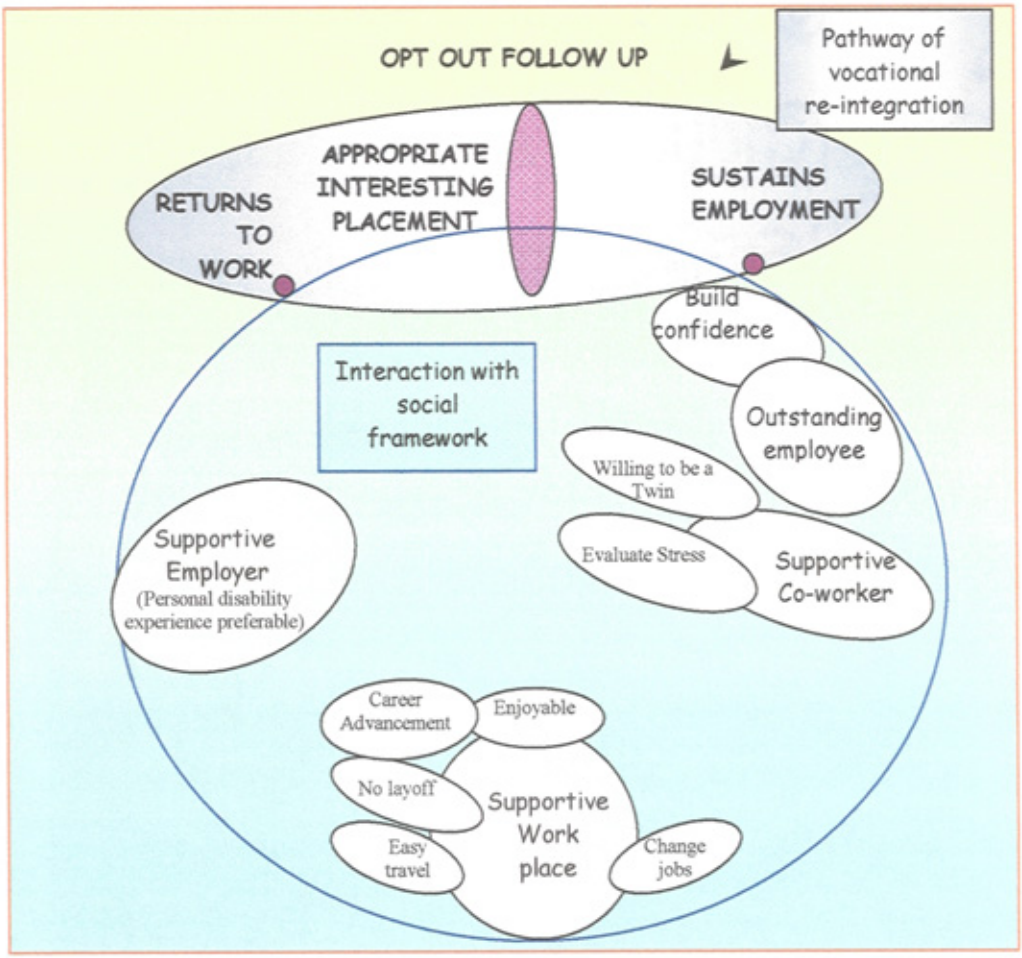
Step 3: Interaction with Social framework.

The next step is the inclusion of the concepts of work and vocational programme support and follow up into the framework. The main requirements of this step are:

1. To provide support from the employer and increase potential for support by identifying supportive employers with a personal experience of disability.
2. To provide support from co-worker by providing a "twin" at work and identifying and dealing with co-worker stress
3. To provide support at the work place by ensuring easy transport, enjoyable job, possibility of change and as little chance of layoff as possible.
4. Opt out follow up, confidence building and the goal of becoming an outstanding employee to be facilitated by the vocational rehabilitation programme.

The practice of these concepts should be available at any time to the vocational re-integration pathway. The interaction of the social framework is shown in Figure 7.4.

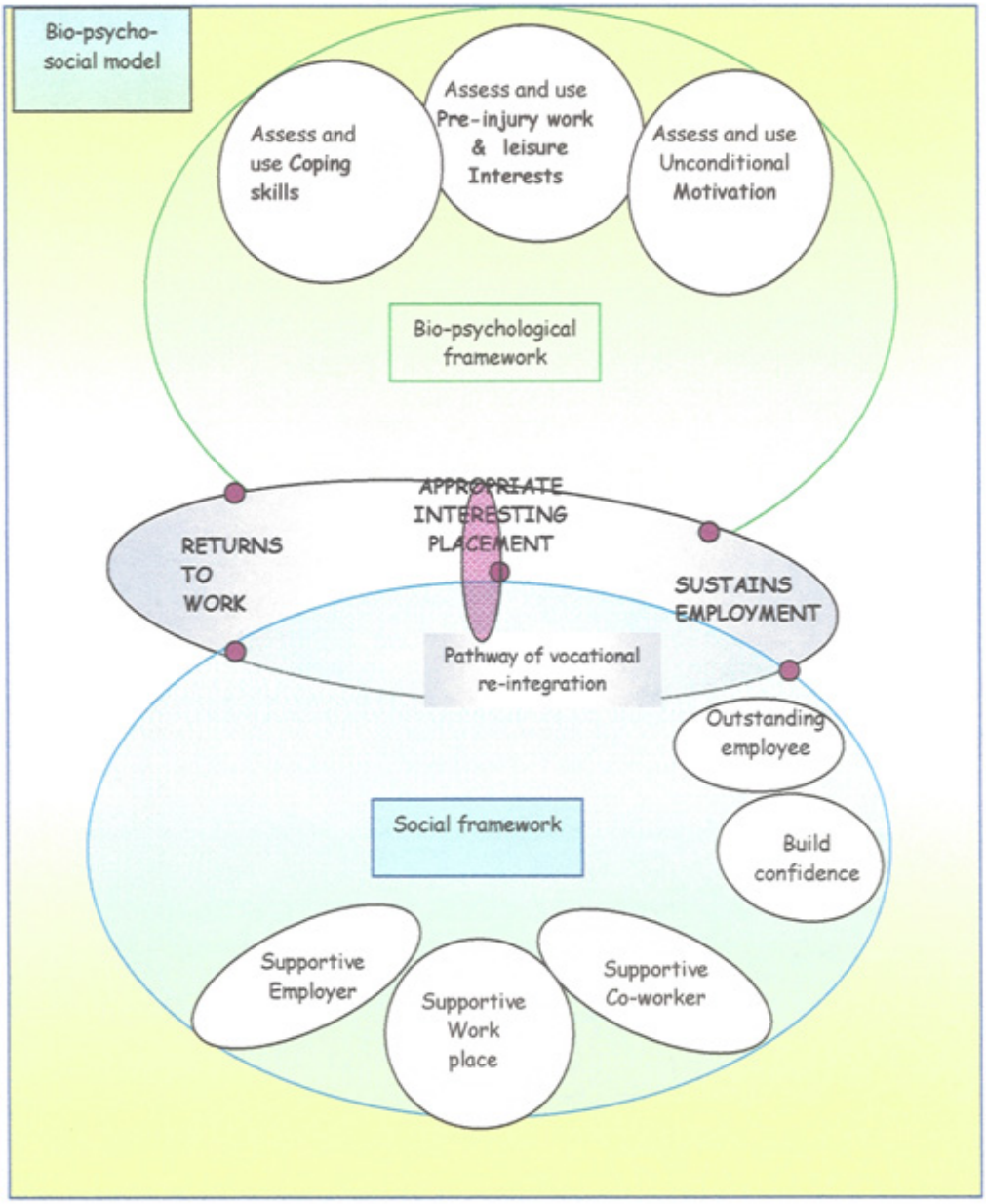
Figure 7.4: Interaction with bio-psychological framework: step 3



Step 4: Integration of framework into an ICF based model

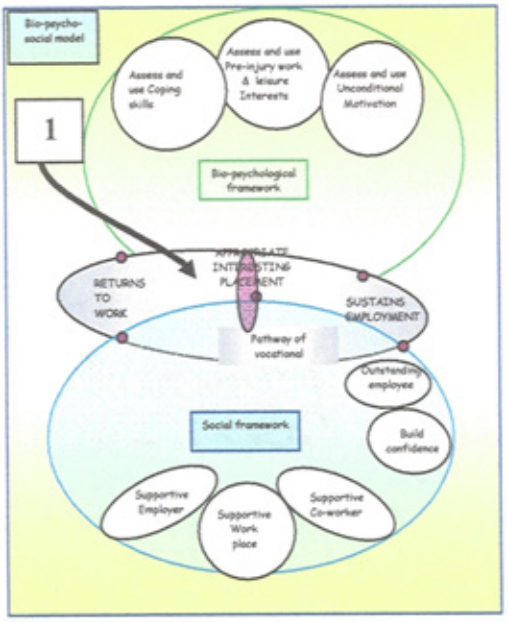
The last step is to integrate processes hitherto described into a single cohesive ICF framework – the 'bio-psycho-social model' (WHO 2001). The requirements of integration are that every stage of the vocational process has access to practices of the bio-psycho-social concepts and that this access can be operated simultaneously if necessary (DH and NSF 2005). The interaction between practices in the bio-psychological framework and supportive individuals or programs in the social framework must be possible. There should be a continuous follow up process and no exit point. This has been demonstrated as a model of overlapping circles with corresponding events occurring at overlapping points on the vocational re-integration cycle as seen in Figure 7.5.

Figure 7.5: Conceptual model for sustaining employment: step 4

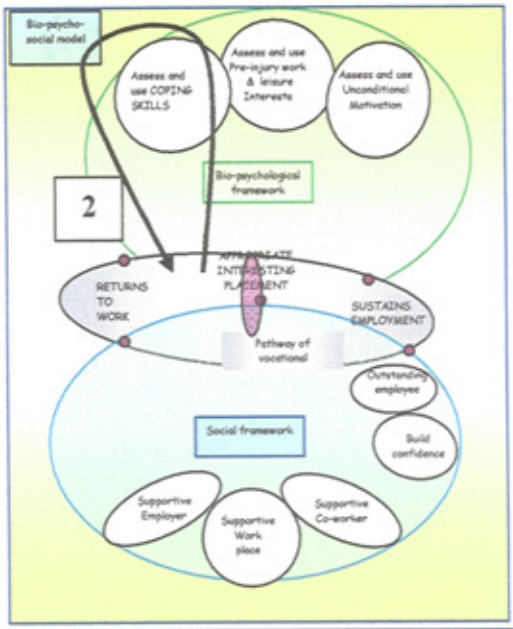


How does the conceptual model work in practice?

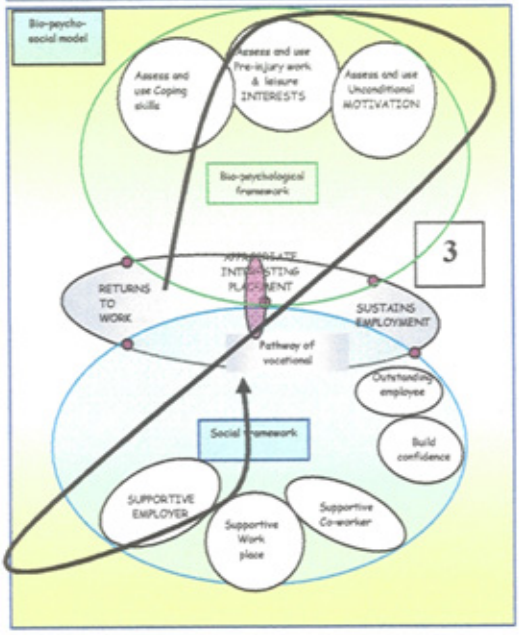
The best way of demonstrating the use of the ICF based conceptual model is by simulation. A hypothetical "meta-case" is described here combining appropriate events from the lives of the interviewees to demonstrate the corresponding pathways in this conceptual model.



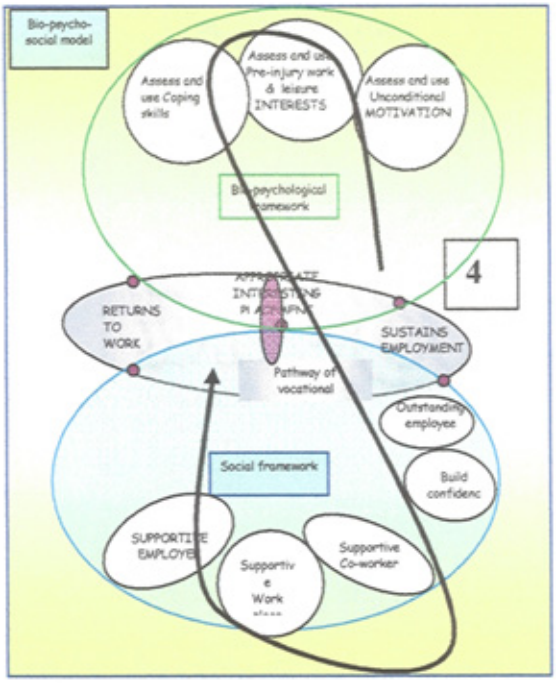
John Smith was 35 years old when he was hit by a car and suffered severe traumatic brain injury. He had a prolonged period of hospital care and after 6 weeks gradually regained consciousness. He slowly regained speech and movement and, after a year in rehabilitation, was able to manage household activities and ambulation independently. He wanted to return to work and was referred to a supported employment programme where he was assessed **(1).**



During the assessment, John realized that he had difficulty in following conversations. He found that if he was in a quiet place, he could manage very well. He could manage only one task at a time and that included conversations. He would practice finding a quiet place in a room and practised ways of getting to a quiet place and learnt to stop himself doing two things at a time **(2)**.

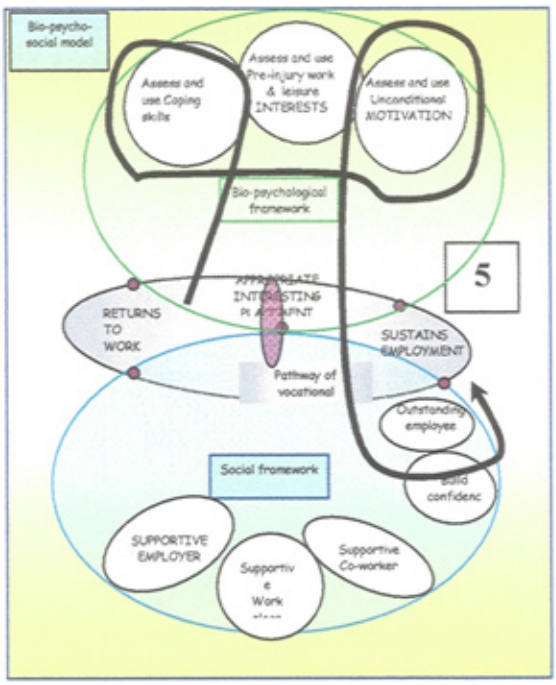


John had always worked in restaurants and had been running a pub for 3 years before the accident but this was no longer a viable option. However he was a very good cook and was still able to dish out excellent meals at home every weekend. He took pride in his recipes though he had to refer back to notes each time. He went to a small pub thrice a week on a placement which was run by a close family friend **(3)**.



The placement went off well but problems were noticed when things got busy. John would lose track of orders if more than 2 came in at a time. However, his excellent culinary skills meant that, friendship apart, his employer was loathe to lose him. He suggested that John only work alternate weekday afternoons when things were quiet but regulars came in. This worked out well and John completed his placement and returned to work **(4)**.

John was now a valued employee and had made friends with other people in the team. His job coach used to visit him regularly and discuss things with John and his employer friend. There were occasional problems when things got busy but John was getting better at managing things. He slowly increased his days at work and found that he could manage things.



Once he got his driving license back, he was able to work late hours and weekends and would pitch in when necessary. He still noticed that a particularly complicated recipe tired him though he could do routine meals without a problem, sometimes managing 8 hours of hard work. His daughter was going to university and he needed the extra money and so after a year, he started working full time and eventually became a partner in the business. His job coach continued to phone him once a year to check if all was well **(5).**

This example demonstrates some of the important issues relevant to sustaining employment and the way in which this conceptual model allows multiple interactions between the vocational process and practices of the bio-psycho-social concepts.

Thus, the conceptual model of vocational rehabilitation demonstrates an integrated biopsychosocial approach with a cyclical rather than a linear framework including practices which are based on relevant bio-psycho-social concepts in sustaining employment. It is compliant with the latest international classification of functioning, health and disability (ICF).

SUMMARY

The aim of the research project was to develop a conceptual model of sustained employment in individuals with ABI. This was achieved through the emergence and use of

- bio-psychological concepts relating to coping skills, motivation and pre-injury characteristics especially work and leisure interests.
- social concepts relating to support from employer, co-worker, work place and vocational programme as well as an opt-out follow up pattern (individuals with ABI continue to be followed up till they decide it is not necessary).

These concepts were used to construct an integrated (bio-psycho-social) conceptual model of sustaining employment based on the ICF framework. The framework moved away from previous return to work models by avoiding a linear, staged approach. All relevant concepts and individuals were included and interactions between components were outlined to help sustain employment.

Chapter 8

CHALLENGES TO THEORY AND PRACTICE

Both bio-psycho-social concepts and the conceptual model challenge existing concepts of vocational rehabilitation. They have implications on both theory and practice and these challenges and implications are discussed below.

How do the results challenge theory?

When the ICF conceptual framework (international classification of functioning, disability and health) was enacted by the WHO in 2001, corresponding changes were not made to conceptual models in vocational rehabilitation. In addition, research design, a lack of long term follow up studies and inconsistent findings were unable to provide a clear understanding of the process of vocational re-integration in ABI. This study found that the emerging concepts in sustaining employment fitted in with the ICF framework [1]. Thus older conceptual models are challenged to include function and environmental factors to the previous triad of impairment, activity and participation.

[1] See Fig 7.5 on page 186

The theoretical framework of service delivery has also been challenged. The previous models were based on linear or step ladder patterns set out in an algorithmic fashion [1]. These designs were not representative of the findings in this study. The multidisciplinary interactions and feedback loops which were evident in clinical practice were conceptualized in this study as overlapping spheres which are always interacting with the rehabilitation process, which in itself is a cycle [2]. This challenges our previous concept of rehabilitation as a linear process.

As described in the literature review, previously reported factors relevant to sustaining employment were based entirely on the views of rehabilitation professionals [3]. The individual with ABI, family member and work colleague had not been researched. This study gives these individuals a chance to challenge older concepts and demonstrates that this is a valuable approach in ABI studies.

How do the results challenge practice?

The themes and the conceptual models challenge several existent practices and demand a change in the way the process of vocational rehabilitation is viewed by service providers, employers and society. These are discussed here.

Changing assessment

Individual with ABI

The findings suggest several pre-injury factors help to sustain employment [1]. This implies that we need to find and use these appropriately. In Rehab UK's programme an understanding of an individual's pre-injury character and interests are limited to their declaration of previous jobs and interests and/or corresponding information from a family member. A detailed discussion of these factors with a previous co-worker would have helped to pre-emptively deal with these situations and sustain employment. Thus the findings suggest that the following assessments of pre-injury characteristics and interests may be beneficial while assessing sustainability :

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[1] See Fig 2.3 (page 53) and Fig 2.4 (page 54)
[2] See Fig 7.5 on page 186
[3] See page 58

- a confidential report from a pre-injury employer
- a detailed exploration of pre- injury work and management skills
- a detailed pre-injury leisure interest profile.

The study suggests that the evaluation of the motivation of the individual with particular emphasis on conditions that determine motivation like the impact of pre-injury work [2] and leisure interests will help improve sustainability. Also, the exploration of a role model whom individuals with ABI respect in their pre-injury life has shown to help motivation in the general rehabilitation process [3]. The study suggests that a role model could improve motivation to sustain employment.

The study challenges assessment priorities by suggesting that driving and public transport assessments [4], a post injury personality and behaviour profile [5] and assessment of motivation for work are valuable assessments in determining sustainability of employment. However the main emphasis of post-injury assessment is for coping strategies. From the research findings, there were several instances of sequelae for which coping or compensatory strategies were lost [6]. Occasionally this had adversely affected employment but had not been recognized before return to work. This finding suggests that, rather than a diagnostic list of sequelae, assessments would need to produce lists of existing and potential coping strategies for mental endurance and fatigue, anger management, basic cognitive, executive and psychiatric impairments.

Employer and Work place

The benefits of having an employer with previous experience of disability and the impact of co-worker stress on sustained employment have been emphasised in this study [7]. This would imply a much closer relationship between the job coach and employers while assessing employer and work place. The personal nature of voluntary disclosure of information requested from employers might be a difficult issue.

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[1] See pages 94 – 103 or summary on p 108
[2] See pages 97,98
[3] See page 107 (Pre-injury family support)
[4] See pages 146-147
[5] See pages 111-118
[6] See pages 138 - 140
[7] See pages 149, 150

However, this research shows that such employers are committed to the cause. A concerted attempt at producing such a list of supportive employers would be of great benefit in the placement process.

Other Rehab UK vocational assessments have been shown o have a positive impact on sustained employment like:

- identifying co-workers to be work twins [1]
- identifying work places with easy transport from home to work [2]
- identifying potential for changing jobs within the same work place [3]
- identifying potential for lay off [4]

These are all transferable parts of an iterative process which is carried out by Rehab UK job coaches and have been shown to help sustainability in the employment process.

Changing patterns of service delivery

The new conceptual model of vocational rehabilitation proposes a feedback process which does not have an endpoint (discharge) planned. This implies a larger case load held by individual job coaches and programmes which bears financial implications (Thornton, Banks *et al.* 2005). However two counter arguments are available: one is the evidence of efficacy of the opt out follow up pattern provided by this research [5]. The other is the econometric argument which shows that in the UK, for instance, such programmes provide a net saving to the exchequer of around £300 a month (Tyerman 1999). In the US, individual earnings of over $17,000 were documented over the cost associated with vocational rehabilitation over a 14 year period (Wehman, Kregel *et al.* 2003). Thus it should be possible to defend a larger programme to financial policy makers.

The integrated ICF based model suggests that changes will be required in job descriptions and in the administrative organization of vocational rehabilitation teams.

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[1] See pages 144, 145
[2] See pages 146 -148
[3] See page 152
[4] See page 152
[5] See pages 153, 154

One of the principles of rehabilitation is matrix organization of the team which indicates that the patient is the centre of the team (DH and NSF 2005). This will be a useful anchor point around which to change patterns of service delivery. Specialist services will need to be available at the work place and employer and co-worker assessments and observations will need to be available to the vocational programme. Thus both the job coach and the individual with ABI will be able to make use of appropriate components of both bio-psychological and social concepts at all stages of the vocational re-integration process.

Two specific difficulties are foreseen in the integrated model. The first is the difficulty of finding trained and experienced staff (Berry and Brownlee 2002). Though it was not associated with sustained employment, training was a concern raised by vocational rehabilitation staff in this study. Thus the skill required for the integrated process might not be easily available. This has already been referred to in other programmes (Lock, Jordan *et al.* 2005). This difficulty can be overcome by imparting specific skills on a case by case basis to other members within the process. Successful examples of this have been seen in the findings of this study where co-workers, family members and individuals themselves are either imparted with knowledge and training, or intuitively, put in coping strategies to help them to sustain employment.

The other difficulty of the integrated model is the legal and confidentiality issue confronting co-workers and employers when discussing work related issues with "outsiders". There were 2 previous supervisors who could not be interviewed in this study. This highlights the difficulties in the logistics of obtaining reports from employers or co-workers. It holds implications for a vocational programme which is trying to include employers and co-workers in the vocational process. Such involvement will need to be cleared previously and protocols of the company or employer involved will need to be followed. A legal confidentiality clause might need to be operated in order to give employers and companies confidence, especially where pre-injury employment is being assessed. However, this study has demonstrated that whenever there were supportive employers, this assessment was perceived as a constructive process. Thus, if these are outlined before the employment process is

started, research and experience suggest that this interaction has been perceived positively.

This study emphasises the development and evaluation of assessment protocols for bio-psychological issues [1]. Individual programmes do use their own versions of questionnaires and check lists and this is an area of future research. There are general references to some checklists used in research in the general population but no evidence to their efficacy or applicability to those with ABI e.g. Ways of coping checklist (Folkman and Lazarus 1980; Grossi 1999), Key behaviour change inventory (Kolitz, Vanderploeg *et al.* 2003), European Brain Injury Questionnaire (EBIQ) and the Karolinska Psychodynamic Profile (KAPP) (Mathiesen and Weinryb 2004). The vocational rehabilitation programme in this study (Rehab UK) had begun to use the Neurobehavioural Functioning Inventory (Kreutzer, Seel *et al.* 1999; Berry and Brownlee 2002) in an attempt to address this need.

Changing perceptions

The data suggests several positive and interesting perceptions of vocational rehabilitation in ABI.

An individual with ABI can become outstanding employees later on as described by this research [2]. People with ABI are often good, if not excellent workers and need to be recognized as such. It is therefore not unrealistic to perceive the goal of sustaining employment in ABI as trying to be the outstanding employee rather than merely keeping a job.

Return to work outcomes in supported employment in ABI (around 75%) are better than the vocational services for general population in the UK (around 40-60%) (Wehman, Kreutzer *et al.* 1990; DWP 2002). Thus, rather than being marketed as a poor cousin of vocational re-integration programmes, the supported employment pattern in ABI needs to be sold as a cost effective, specialist model and a "big brother" of general vocational re-integration programmes.

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[1] See pages 168, 182
[2] See pages 145, 146

The benefits of placement (a "free 6 week interview" with no strings attached at the end and no financial loss in the process) has appealed to employers. This research gives evidence to support the advantages of appropriate, interesting placements helping to provide outstanding employees [1]. It suggests a very positive perception to work placements as there is evidence that work placements have the potential to be of great benefit (and no loss) to potential employers.

Transferability

Many of the findings from this study are transferable to other programmes involved in sustaining employment. This is particularly applicable for the vocational programme in the researcher's home institution i.e. the Rehabilitation Institute of Christian Medical College Vellore, India.

The principles and design of the proposed conceptual model for sustaining employment are applicable to any similar supported employment programme for individuals with ABI. The findings suggest that vocational programmes will benefit by providing continued access to service at all stages of follow up. Instead of conceptualizing the vocational process in the traditional step ladder pattern [2], vocational programmes could benefit from thinking of the process as a cyclical design as proposed in this study. This cyclical conceptual model will help in planning and integration of bio-psychological and social components of the programme as suggested by the ICF [3]. It will also help the programme to conceptualize and defend the offer of continued access to the service by the individuals with ABI. This may improve sustained employment.

Biopsychosocial components in these programmes are the key transferable findings which emerged in the development of the conceptual model. This study demonstrates the benefits of Rehab UK's assessment and rehabilitation process and these findings are transferable to other similar programmes. Thus, detailed assessments of pre-injury

[1] See page 156
[2] See Fig 2.3 (page 53) and Fig 2.4 (page 54)
[3] See Fig 7.5 on page 186

employment, assessments of personality, behaviour, interests and motivation, fatigue and psychiatric symptoms are examples of bio-psychological factors which can be adopted by other vocational rehabilitation programmes to improve sustained employment [1].

The benefits of supportive employers with a personal experience of disability [2] and co-workers who are willing to be twinned [3] are some of the social factors which have helped sustainability in the individuals with ABI in this study. Vocational rehabilitation programmes could actively seek the support of such individuals.

Examples of outstanding employees serve as challenging stories for service providers and individuals with ABI and encourage people to change their perceptions of working patterns of individuals with ABI. There have been examples in the study of individuals overcoming alcoholism [4] as well as individuals who have sustained employment despite financial disincentives [5]. These examples have counter-balanced the traditional bias against substance abuse and financial disincentives. Thus transferability of these findings help us re-think approaches to individuals with ABI.

The findings of this study are also transferable to individual clinical practice. The stories of individuals with ABI as described in Appendix C are not unfamiliar in clinical practice. The researcher has found various individualized approaches to sustain employment are also transferable to similar new clinical situations –even in cross cultural settings. In particular, this study demonstrated that an individual's coping strategies would be able to overcome their cognitive, psychiatric and neurobehavioural challenges [6]. This finding has encouraged a focus on identifying or developing coping strategies in individual clinical situations in the researcher's practice. As mentioned before, there have been examples of individuals who have used their pre-injury leisure interests to improve motivation and sustain employment.

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[1] See Fig 7.1 on page 168
[2] See pages 149, 150
[3] See pages 144, 145
[4] See pages 107, 108
[5] See pages 159 - 161
[6] See pages 138 - 140

This has encouraged a search for similar leisure interests in individual cases. Thus, findings from the study have also been transferred to individual clinical situations.

Limitations of the research project

One of the major limitations in the initial part of the project was the narrow literature base of research on return to work. These limitations were magnified when literature was searched for research on sustained employment. There were even fewer studies on sustaining employment after return to work.

Apart from the paucity of research, existing studies in the area of return to work and sustained employment had the following drawbacks:

- Vocational rehabilitation programmes were not standardised.
- Individuals with ABI presented with highly variable characteristics.
- Outcomes were not standardized.
- There were very few studies with good methodological characteristics [1].

Methodologically there were some limitations in adopting a qualitative approach for this study:

- It was not possible to calculate the probability of chance affecting the results.
- Statistically predictive models could not be constructed.
- The natural exclusion criteria operating in vocational rehabilitation programmes limit the application of this study only to individuals who have undergone a supported employment programme.

When topics discussed by participants were not directly mentioned as being linked to sustaining employment (termed as 'indirect association"), these were not included in the development of the conceptual model. While this improves rigour in the analytical process, it may limit rich analysis in the research project as it is possible to lose results which could have been derived from the analysis of indirect associations [2].

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[1] Approaches to research design used to contain these limitations are described on pages 62-65.
[2] The implications of indirect associations are described on pages 174-178.

Future actions for research

This study has built up a triangulated body of evidence to propose an integrated conceptual model of vocational rehabilitation in ABI with specific emphasis on metacognitive, pre-injury, work and vocational rehabilitation factors [1]. This proposed model will need to be piloted and evaluated. Assessment tools of motivation, coping skills and pre-injury factors need to be explored, standardized and validated for individuals with ABI. Quantifying the probability of chance in this area of knowledge will be dependent on finding good outcome measures based on these assessment tools which will hopefully emerge in the future.

Long term follow up of the employment process (beyond 2 years) in individuals with ABI is still an area of research need.

The study has raised questions of comparisons between supported employment for ABI and the programmes in the general population [2]. This will need to be explored as a comparative study might have interesting applications for unemployed individuals with ABI and those in the general population.

Not only have aims and objectives been fulfilled but the semi structured interviews gave opportunity and voice to "insiders" – all those involved with the process of vocational rehabilitation. It has been proposed that research in rehabilitation should empower those who are being researched by amplifying their voice (Brown and Gordon 2004). It is hoped that further dissemination of this research would amplify the voices of the research participants and vicariously empower them.

[1] See Fig 7.5 on page 186
[2] See page 194

SUMMARY

The conceptual model of sustaining employment suggests a paradigm shift in the focus of future research and services. It suggests a shift from the current understanding of ABI sequelae which comprise of physical, cognitive and neuropsychological sequelae to a more specific set of bio-psychological factors like motivation, coping skills and pre-injury factors especially previous work and leisure interests. The factors relating to work and vocational rehabilitation, especially with regard to providing support also suggest a change to the conceptual model of vocational rehabilitation and to the pattern of follow up. The study proposes the adoption of an 'opt-out' follow up pattern and proposes greater roles for employers and co-workers in the process of sustaining employment.

The new conceptual model that has been proposed challenges existing practice in three main areas.

1. It suggests a change in emphasis in the assessment of ABI sequelae and advocates broadening the scope of work related assessments.
2. It suggests closer integration in patterns of service delivery.
3. It suggests a change in the way we perceive the employment potential of individuals with ABI who have demonstrated their ability to be outstanding employees in this study.

Finally, the conceptual model of vocational rehabilitation has several pragmatic implications for future research and service. It suggests further research is needed on transferability of these findings to other projects and on long term follow up. It suggests that validated assessment tools based on the new conceptual model need to be developed.

CHAPTER 9

CONCLUSION

In conclusion, the aim of the study was to develop a conceptual model of why individuals with acquired brain injury who have successfully participated in vocational rehabilitation were able or unable to sustain their jobs. This conceptual model has been developed and discussed.

Triangulated data provided a new understanding of *bio-psychological concepts* in sustaining employment – primarily **motivation, coping skills and pre-injury work and leisure interests**. It also suggested that inter-relationships between these factors could help sustain employment e.g. pre-injury leisure interest could improve motivation and help sustain employment.

A more specific understanding of *social concepts* in sustaining employment was also obtained through this study. A re-emphasis of **support from the employer, co-worker, vocational rehabilitation programme and work place** was made. An **opt-out follow up pattern** was suggested by participants i.e. when follow up for the individuals with ABI is continued till they request otherwise.

The conceptual model emerging from these concepts was compliant with the ICF and proposes a cyclical continuum rather than a staged and linear approach. It advocates a greater role for employers and co-workers (pre and post-injury) in the process of employment.

The new conceptual model challenges several areas of practice. It challenges the methods of assessment currently used by suggesting assessments of motivation, coping skills and pre-injury interests. It also challenges the patterns of service delivery by demanding an integrated approach at all levels and an "opt-out" follow up pattern i.e. continued follow up till the individual with ABI requests that it be withdrawn.

It also opens out several research challenges primarily in the area of development of assessment tools for motivation, coping skills and pre-injury interests. It suggests that research is needed to evaluate current practice of vocational rehabilitation in ABI in comparison to services available for the unemployed in the general population. It also leads on to the question of transferability of findings to other projects and similar situations in ABI rehabilitation.

Finally, this research study has empowered the "insiders" in the process of vocational rehabilitation by giving them a voice. They demand a change in our perceptions. Employers, rehabilitation professionals, families and society need to change their perceptions of the vocational potential of those with ABI as this study has demonstrated that individuals with Acquired Brain Injury can be outstanding employees.

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APPENDIX A

INFORMATION SHEETS AND CONSENT FORMS

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR

Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

CLIENT INFORMATION SHEET & CONSENT FORM

(Those not sustaining employment)

Study title: Sustaining employment in a supported employment programme for people with acquired brain injury

Invitation

You are being invited to take part in a research study to look at **WHY SOME PEOPLE WHO COMPLETE THE REHAB UK PROGRAMME AND RETURN TO WORK FIND IT DIFFICULT TO KEEP THEIR JOBS.**
Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to **read** the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

What is the purpose of the study?

Rehab UK uses the best known approach to help people with brain injury return to work. Despite this, there are still a few who, for a variety of reasons, still find it difficult to keep their jobs. I would like to identify these reasons. Therefore I would like to interview people like you who have completed the Rehab UK programme more than a year ago. I plan to analyse all these interviews and information and compare those like yourself who find it difficult to sustain their jobs with others who have been able to do so. I hope to develop a theory of why some people find it difficult to keep their jobs.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

You will be given a clinical neurological examination (much like the examination that you would have experienced at a rehabilitation or neurology clinic), cognitive testing and fairly detailed, taped interviews. This will take around an hour each and the place and time can be arranged according to your convenience.

I would also interview a close relative, a co-worker and staff involved with your rehabilitation at Rehab UK or elsewhere about the time around your brain injury and the Rehab UK programme.

I plan to complete interviews by 2004.

What are the possible disadvantages and risks of taking part?

From previous experience I expect that there is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this. If the need for referral arises, appropriate appointments can be arranged.

What are the possible benefits of taking part?

The information we get from this study may help us to decrease job loss in those completing the Rehab UK programme. If you wish, a summary of key issues around your vocational life will be available either to you or to Rehab UK at the end of the study. This will be useful feedback to you and if you wish, Rehab UK could also use your data to improve their follow up plan for you.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, there will be no change in your previous follow up arrangements with Rehab UK. If you decide to continue in the study you will be asked to sign an updated consent form.

What if something goes wrong?

If you are unhappy about any of examination, tests or interviews, please contact me and I will do my best to redress the situation. If I cannot, or if you feel you need to talk about your complaint to someone else, please contact my guide and the consultant clinical psychologist at Rehab UK, Mr. Alister Berry (Phone 0191 2320234).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed once written and analysis is completed. Coding will be used at the time of writing and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it. As mentioned before, if you would like to have detailed analyses of your interview set, this could be provided.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at Northumbria University and the Tyne and Wear centre of Rehab UK. Subsequent publication will be subject to procedures in the appropriate journal. You will not be identified in any report/publication.

Who is organising and funding the research?

I am a doctor (specialist registrar) with experience in Rehabilitation since 1993. I am working in the Hunters Moor Regional Neurological Rehabilitation Centre of the Northgate and

Prudhoe NHS Trust who will be sponsoring my research. I am conducting this research as part of my PhD with Northumbria University and will be collaborating with Rehab UK, all in Newcastle upon Tyne. No financial sponsorship is involved.

Who has reviewed the study?

1. NHS Local Research Ethics Committees.
2. Northgate and Prudhoe NHS Trust Research & Development committee.

Contact for Further Information

Dr Ashish Stephen Macaden,
Specialist Registrar in Rehabilitation Medicine,
Hunters Moor Regional Neurorehabilitation Centre,
Hunters Road,
Newcastle upon Tyne NE2 4NR.
Phone: 0191 219 5661

Please keep this information sheet and a copy of the signed consent form.
Thank you for reading this.

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR

Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

CLIENT INFORMATION SHEET & CONSENT FORM

(Those sustaining employment)

Study title: Sustaining employment in a supported employment programme for people with acquired brain injury

Invitation

You are being invited to take part in a research study to look at **WHY SOME PEOPLE WHO COMPLETE THE REHAB UK PROGRAMME AND RETURN TO WORK FIND IT DIFFICULT TO KEEP THEIR JOBS.**
Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to **read** the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

What is the purpose of the study?

Rehab UK uses the best known approach to help people with brain injury return to work. Despite this, there are still a few who, for a variety of reasons, still find it difficult to keep their jobs. I would like to identify these reasons. Therefore I would like to interview people like you who have completed the Rehab UK programme more than a year ago. I plan to analyse all these interviews and information and compare those like yourself who have been able to sustain their jobs with others who find it difficult to do so. I hope to develop a theory of why some people find it difficult to keep their jobs.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?

You will be given a clinical neurological examination (much like the examination that you would have experienced at a rehabilitation or neurology clinic), cognitive testing and fairly detailed, taped interviews. This will take around an hour each and the place and time can be arranged according to your convenience.

I would also interview a close relative, a co-worker and staff involved with your rehabilitation at Rehab UK or elsewhere about the time around your brain injury and the Rehab UK programme.

I plan to complete interviews by 2004.

What are the possible disadvantages and risks of taking part?

From previous experience I expect that there is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this. If the need for referral arises, appropriate appointments can be arranged.

What are the possible benefits of taking part?

The information we get from this study may help us to decrease job loss in those completing the Rehab UK programme. If you wish, a summary of key issues around your vocational life will be available either to you or to Rehab UK at the end of the study. This will be useful feedback to you and if you wish, Rehab UK could also use your data to improve their follow up plan for you.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, there will be no change in your previous follow up arrangements with Rehab UK. If you decide to continue in the study you will be asked to sign an updated consent form.

What if something goes wrong?

If you are unhappy about any of examination, tests or interviews, please contact me and I will do my best to redress the situation. If I cannot, or if you feel you need to talk about your complaint to someone else, please contact my guide and the consultant clinical psychologist at Rehab UK, Mr. Alister Berry (Phone 0191 2320234).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed once written and analysis is completed. Coding will be used at the time of writing and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it. As mentioned before, if you would like to have detailed analyses of your interview set, this could be provided.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at Northumbria University and the Tyne and Wear centre of Rehab UK. Subsequent publication will be subject to procedures in the appropriate journal. You will not be identified in any report/publication.

Who is organising and funding the research?

I am a doctor (specialist registrar) with experience in Rehabilitation since 1993. I am working in the Hunters Moor Regional Neurological Rehabilitation Centre of the Northgate and Prudhoe NHS Trust who will be sponsoring my research. I am conducting this research as

part of my PhD with Northumbria University and will be collaborating with Rehab UK, all in Newcastle upon Tyne. No financial sponsorship is involved.

Who has reviewed the study?

3. NHS Local Research Ethics Committees.
4. Northgate and Prudhoe NHS Trust Research & Development committee.

Contact for Further Information

Dr Ashish Stephen Macaden,
Specialist Registrar in Rehabilitation Medicine,
Hunters Moor Regional Neurorehabilitation Centre,
Hunters Road,
Newcastle upon Tyne NE2 4NR.
Phone: 0191 219 5661

Please keep this information sheet and a copy of the signed consent form.
Thank you for reading this.

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR
Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM - A

Title of Project:
SUSTAINING EMPLOYMENT IN A SUPPORTED EMPLOYMENT PROGRAMME FOR PEOPLE WITH ACQUIRED BRAIN INJURY

Name of Researcher: Dr Ashish Stephen Macaden

Please initial box

1. I confirm that I have read and understand the information sheet dated 6 October 2002 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my interviews / from Hunters Moor may be looked at by responsible individuals from Hunters Moor Regional Neurorehabilitation Centre, Northumbria University or Rehab UK, where it is relevant to my taking part in research. I give permission for these individuals to have access to my interviews / medical notes. ☐
4. I agree to my relative / primary carer, co worker and staff of Rehab UK being interviewed about me. ☐
5. I agree to take part in the above study. ☐

Name of Subject	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Subject's copy/ Researcher's copy/ Rehab UK copy

☐ I would like to have a summary of key issues related to my vocational rehabilitation.

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR

Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

RELATIVE'S INFORMATION SHEET & CONSENT FORM

Study title: Sustaining employment in a supported employment programme for people with acquired brain injury

Invitation

You are being invited to take part in a research study to look at **WHY SOME PEOPLE WHO COMPLETE THE REHAB UK PROGRAMME AND RETURN TO WORK FIND IT DIFFICULT TO KEEP THEIR JOBS.**

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to **read** the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

Rehab UK uses the best known approach to help people with brain injury return to work. Despite this, there are still a few who, for a variety of reasons, still find it difficult to keep their jobs. I would like to identify these reasons. As a close relative of a person who has completed the Rehab UK programme, your view regarding this will be very important to our understanding of this situation.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your relative receives.

What will happen to me if I take part?

You will be interviewed regarding your relative and your experience with them. This will be taped and take around an hour. The place and time of the interview can be arranged according to your convenience.

I would also interview your relative, a co-worker and staff involved with their rehabilitation at Rehab UK or elsewhere (taped interviews or written records) about their experience around the time of the brain injury and the Rehab UK programme.

I plan to complete interviews by 2004.

I plan to complete interviews by 2004.

What are the possible disadvantages and risks of taking part?

Apart from the time spent on interviews, there is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this. If the need for referral arises, appropriate appointments can be arranged for your relative.

What are the possible benefits of taking part?

The information we get from this study may help us to decrease job loss for those completing the Rehab UK programme. If your relative wishes, a summary of key issues around their vocational life will be made available either to them or Rehab UK at the end of the study. This will be useful feedback and Rehab UK could also use your data to improve their follow up plan for them.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, there will be no change in your relative's previous follow up arrangements with Rehab UK. If you decide to continue in the study you will be asked to sign an updated consent form.

What if something goes wrong?

If you are unhappy about any of examination, tests or interviews, please contact me and I will do my best to redress the situation. If I cannot, or if you feel you need to talk about your complaint to someone else, please contact my guide and the consultant clinical psychologist at Rehab UK, Mr. Allster Berry (Phone 0191 2320234).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed once written and analysis is completed. Coding will be used at the time of writing and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it. As mentioned before, if your relative would like to have detailed analyses of the interview set, this could be provided.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at Northumbria University and the Tyne and Wear centre of Rehab UK. Subsequent publication will be subject to procedures in the appropriate journal. You will not be identified in any report/publication.

Who is organising and funding the research?

I am a doctor (specialist registrar) with experience in Rehabilitation since 1993. I am working in the Hunters Moor Regional Neurological Rehabilitation Centre of the Northgate and Prudhoe

NHS Trust who will be sponsoring my research. I am conducting this research as part of my PhD with the Northumbria University and will be collaborating with Rehab UK, all in Newcastle upon Tyne. No financial sponsorship is involved.

Who has reviewed the study?

1. NHS Local Research Ethics Committees.
2. Northgate and Prudhoe NHS Trust Research & Development committee.

Contact for Further Information

Dr Ashish Stephen Macaden,
Specialist Registrar in Rehabilitation Medicine,
Hunters Moor Regional Neurorehabilitation Centre,
Hunters Road,
Newcastle upon Tyne NE2 4NR.
Phone: 0191 219 5661

Please keep this information sheet and a copy of the signed consent form.

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR
Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM - B

Title of Project:
SUSTAINING EMPLOYMENT IN A SUPPORTED EMPLOYMENT PROGRAMME FOR PEOPLE WITH ACQUIRED BRAIN INJURY

Name of Researcher: **Dr Ashish Stephen Macaden**

Please initial box

1. I confirm that I have read and understand the information sheet dated 8 October 2002 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that sections of any of my interviews may be looked at by responsible individuals from Hunters Moor Regional Neurorehabilitation Centre, Northumbria University or Rehab UK, where it is relevant to my taking part in research. I give permission for these individuals to have access to my interviews. ☐
4. I agree to take part in the above study. ☐

Name of Subject	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Subject's copy/ Researcher's copy/ Rehab UK copy

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR

Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

CO-WORKER'S INFORMATION SHEET & CONSENT FORM

Study title: Sustaining employment in a supported employment programme for people with acquired brain injury

Invitation

You are being invited to take part in a research study to look at **WHY SOME PEOPLE WHO COMPLETE THE REHAB UK PROGRAMME AND RETURN TO WORK FIND IT DIFFICULT TO KEEP THEIR JOBS.**

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to **read** the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

Rehab UK uses the best known approach to help people with brain injury return to work. Despite this, there are still a few who, for a variety of reasons, still find it difficult to keep their jobs. I would like to identify these reasons. As a co-worker of a person who has completed the Rehab UK programme, your view regarding this will be very important to our understanding of this situation.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your co-worker receives.

What will happen to me if I take part?

You will be interviewed regarding your co-worker and your experience with them. This will be taped and take around an hour. The place and time of the interview can be arranged according to your convenience.

I would also interview your co-worker, their close relative and staff involved with their rehabilitation at Rehab UK or elsewhere (taped interviews or written records) about their experience around the time of the brain injury and the Rehab UK programme.

I plan to complete interviews by 2004.

What are the possible disadvantages and risks of taking part?

Apart from the time spent on interviews, there is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this. If the need for referral arises, appropriate appointments can be arranged for your co-worker.

What are the possible benefits of taking part?

The information we get from this study may help us to decrease job loss for those completing the Rehab UK programme. If your co-worker wishes, a summary of key issues around their vocational life will be made available either to them or Rehab UK at the end of the study. This will be useful feedback and Rehab UK could also use your data to improve their follow up plan for them.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, there will be no change in your co-worker's previous follow up arrangements with Rehab UK. If you decide to continue in the study you will be asked to sign an updated consent form.

What if something goes wrong?

If you are unhappy about any of examination, tests or interviews, please contact me and I will do my best to redress the situation. If I cannot, or if you feel you need to talk about your complaint to someone else, please contact my guide and the consultant clinical psychologist at Rehab UK, Mr. Alister Berry (Phone 0191 2320234).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed once written and analysis is completed. Coding will be used at the time of writing and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it. As mentioned before, if your co-worker would like to have detailed analyses of the interview set, this could be provided.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at Northumbria University and the Tyne and Wear centre of Rehab UK. Subsequent publication will be subject to procedures in the appropriate journal. You will not be identified in any report/publication.

Who is organising and funding the research?

I am a doctor (specialist registrar) with experience in Rehabilitation since 1993. I am working in the Hunters Moor Regional Neurological Rehabilitation Centre of the Northgate and Prudhoe

NHS Trust who will be sponsoring my research. I am conducting this research as part of my PhD with the Northumbria University and will be collaborating with Rehab UK, all in Newcastle upon Tyne. No financial sponsorship is involved.

Who has reviewed the study?

1. NHS Local Research Ethics Committees.
2. Northgate and Prudhoe NHS Trust Research & Development committee.

Contact for Further Information

Dr Ashish Stephen Macaden,
Specialist Registrar in Rehabilitation Medicine,
Hunters Moor Regional Neurorehabilitation Centre,
Hunters Road,
Newcastle upon Tyne NE2 4NR.
Phone: 0191 219 5661

Please keep this information sheet and a copy of the signed consent form.

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR
Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM - C

Title of Project:
SUSTAINING EMPLOYMENT IN A SUPPORTED EMPLOYMENT PROGRAMME FOR PEOPLE WITH ACQUIRED BRAIN INJURY

Name of Researcher: Dr Ashish Stephen Macaden

Please initial box

1. I confirm that I have read and understand the information sheet dated 8 October 2002 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that sections of any of my interviews may be looked at by responsible individuals from Hunters Moor Regional Neurorehabilitation Centre, Northumbria University or Rehab UK, where it is relevant to my taking part in research. I give permission for these individuals to have access to my interviews. ☐

4. I agree to take part in the above study. ☐

Name of Subject	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Subject's copy/ Researcher's copy/ Rehab UK copy

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR
Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

REHABILITATION SERVICE PROVIDER'S INFORMATION SHEET & CONSENT FORM

Study title: Sustaining employment in a supported employment programme for people with acquired brain injury

Invitation

You are being invited to take part in a research study to look at **WHY SOME PEOPLE WHO COMPLETE THE REHAB UK PROGRAMME AND RETURN TO WORK FIND IT DIFFICULT TO KEEP THEIR JOBS.**

Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. **Ask us** if there is anything that is not clear or if you would like more information. Take time to **decide** whether or not you wish to take part.

Rehab UK uses the best known approach to help people with brain injury return to work. Despite this, there are still a few who, for a variety of reasons, still find it difficult to keep their jobs. I would like to identify these reasons. As a co-worker of a person who has completed the Rehab UK programme, your view regarding this will be very important to our understanding of this situation.

Do I have to take part?

Taking part in the research is entirely voluntary. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your client receives.

What will happen to me if I take part?

You will be interviewed regarding your client and your experience with them. This will be taped and take around an hour. The place and time of the interview can be arranged according to your convenience.

I would also interview your client, their close relative and their co-worker (taped interviews or written records) about their experience around the time of the brain injury and the Rehab UK programme.

I plan to complete interviews by 2004.

What are the possible disadvantages and risks of taking part?

Apart from the time spent on interviews, there is the possibility that the interviews would bring up sensitive issues that you may wish to discuss further. This is not unusual and should you feel the need to extend the discussion, we can set apart time for this. If the need for referral arises, appropriate appointments can be arranged for your client.

What are the possible benefits of taking part?

The information we get from this study may help us to decrease job separations for those completing the Rehab UK programme. If your client wishes, a summary of key issues around their vocational life will be made available either to them or Rehab UK at the end of the study. This will be useful feedback and Rehab UK could also use your data to improve their follow up plan for them.

What if new information becomes available or if I change my mind?

If additional information becomes available or if you change your mind during the course of the research, we will discuss whether you want to continue in the study. If you decide to withdraw, there will be no change in your client's previous follow up arrangements with Rehab UK. If you decide to continue in the study you will be asked to sign an updated consent form.

What if something goes wrong?

If you are unhappy about the interviews, please contact me and I will do my best to redress the situation. If I cannot, or if you feel you need to talk about your complaint to someone else, please contact my guide and the consultant clinical psychologist at Rehab UK, Mr. Alister Berry (Phone 0191 2320234).

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you.

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Taped recording of the interviews will be destroyed once written and analysis is completed. Coding will be used at the time of writing and the key to the codes will be kept in a separate, locked cabinet. Any information about you which I submit will have your name and address removed so that you cannot be recognised from it. As mentioned before, if your client would like to have detailed analyses of the interview set, this could be provided.

What will happen to the results of the research study?

On successful completion of the research project, the results will be available at the Northumbria University. Subsequent publication will be subject to procedures in the appropriate journal. You will not be identified in any report/publication.

Who is organising and funding the research?

I am a doctor (specialist registrar) with experience in Rehabilitation since 1993. I am working in the Hunters Moor Regional Neurological Rehabilitation Centre of the Northgate and Prudhoe NHS Trust who will be sponsoring my research. I am conducting this research as part of my

PhD with the Northumbria University and will be collaborating with Rehab UK, all in Newcastle upon Tyne. No financial sponsorship is involved.

Who has reviewed the study?

1. NHS Local Research Ethics Committees.
2. Northgate and Prudhoe NHS Trust Research & Development committee.

Contact for Further Information

Dr Ashish Stephen Macaden,
Specialist Registrar in Rehabilitation Medicine,
Hunters Moor Regional Neurorehabilitation Centre,
Hunters Road,
Newcastle upon Tyne NE2 4NR.
Phone: 0191 219 5661

Please keep this information sheet and a copy of the signed consent form.

Northgate and Prudhoe NHS
NHS Trust

Regional Neurological Rehabilitation Centre
Hunters Road
Newcastle upon Tyne
NE2 4NR
Switchboard: 0191 219 5661
Tel/Fax: 0191 219 5690

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM - D

Title of Project:
SUSTAINING EMPLOYMENT IN A SUPPORTED EMPLOYMENT PROGRAMME FOR PEOPLE WITH ACQUIRED BRAIN INJURY

Name of Researcher: **Dr Ashish Stephen Macaden**

Please initial box

1. I confirm that I have read and understand the information sheet dated 6 October 2002 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected ☐

3. I understand that sections of any of my interviews may be looked at by responsible individuals from Hunters Moor Regional Neurorehabilitation Centre, Northumbria University or Rehab UK, where it is relevant to my taking part in research. I give permission for these individuals to have access to my interviews. ☐

4. I agree to take part in the above study. ☐

Name of Subject	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Subject's copy/ Researcher's copy/ Rehab UK copy

APPENDIX B

ADDENBROKE'S COGNITIVE EXAMINATION

ADDENBROOKE'S COGNITIVE EXAMINATION (ACE)

Name:
Date of birth:
Hospital no.:
Addressograph

Age at leaving education : _____
(school/college etc.)
Date of testing : ___ / ___ / ___
Tester's name : _____

ORIENTATION

(a) What is the Year _____
Season _____
Date ±2 _____
Record errors. Days _____
Month _____
[*Score* 0 - 5]

b) Where are we Country _____
County _____
Town _____
Record errors. Hospital/building _____
Floor *Allow if almost correct.* _____
[*Score* 0 - 5]

REGISTRATION

Name three unrelated objects, taking one second to say each: eg. **lemon, key & ball.** Say them once only and ask the patient to repeat all three. *Give one point for each correct answer at first attempt.*
If score <3 repeat the items until the patient learns all three [0 - 3]

ATTENTION / CONCENTRATION

Ask the patient to begin with **100** and and subtract **7**, and keep subtracting 7.
Stop after five subtractions (93, 86, 79, 72, 65). *Score the total number of correct subtractions.*
If score <5 : Spell **WORLD** backwards. *Score is the number of letters in the correct order, eg dlorw= 3.*
Take score of better of the two tasks. Record errors: _____ [0 - 5]

RECALL

Ask for the names of the three objects learned in question 3. *One point for each answer.* [0 - 3]

MEMORY

(a) **Anterograde Memory:**
Read the name and address and ask the patient to repeat it once you have finished. Regardless of the score after the first trial, repeat the task twice in exactly the same way. *Record errors at each trial.*

	1st trial	2nd	3rd	5 min delay
Peter Marshall	_____	_____	_____	_____
42 Market Street	_____	_____	_____	_____
Chelmsford	_____	_____	_____	_____
Essex	_____	_____	_____	_____
	/7	/7	/7	/7

Trial 1–3 [0 - 21]
5 min delay [0 - 7]

(b) Retrograde Memory: Name of PM _____
Last PM _____
Record errors. Opposition Leader _____
USA President _____
[0 - 4]

(revised 2000)

(c) Comprehension

single-step commands
- 'point to the door'
- 'point to the ceiling' [0 - 2] ☐
- show written instruction: [0 - 1] ☐

CLOSE YOUR EYES

3-stage command
- 'Take the paper in your hand. Fold the paper in half. Put the paper on the floor.'
  Score 1 for each correctly performed step. [0 - 3] ☐

complex grammar
- 'point to the ceiling then the door'
- 'point to the door after touching the bed/desk'
  Score 1 for each correctly performed command. [0 - 2] ☐

(d) Repetition

single words
- 'brown'
- 'conversation'
- 'articulate' [0 - 3] ☐

phrases
- 'No ifs, ands, or buts.' [0 - 1] ☐
- 'The orchestra played and the audience applauded.' [0 - 1] ☐

(e) Reading

- shed
- wipe
- board
- flame
- bridge *Score 1 if all regular words correct.* [0 - 1] ☐

- sew
- pint
- soot
- dough
- height *Score 1 if all irregular words correct.* [0 - 1] ☐

(f) Writing

Ask the patient to make up a sentence and write it down in the space below.
If stuck, suggest a topic e.g. weather, journey to hospital.
Score 1 for a correct subject and verb in a meaningful sentence.

_____ [0 - 1] ☐

NOW CHECK delayed recall of name and address. Record errors on page 1 and enter result into box.

VERBAL FLUENCY

(a) Letters — Ask the patient 'tell me as many words as you can think of beginning with the letter P, but not people and places. You have one minute to go'

(b) Animals — In the same way ask the patient to generate the names of as many animals as possible in one minute, beginning with any letter of the alphabet.
Record all responses. Error types: perseverations and intrusions.

P		Animals	
(start here)	*(continue)*	*(start here)*	*(continue)*

Animal	P	Score
>21	>17	7
17–21	14–17	6
14–16	11–13	5
11–13	8–10	4
9–10	6–7	3
7–8	4–5	2
<7	<4	1

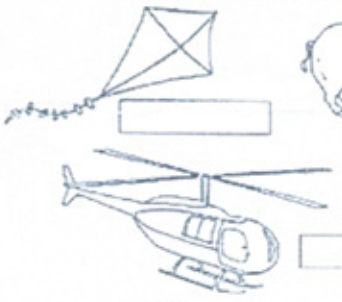
P: Total _____ No. correct _____ [0 - 7] ☐

Animals: Total _____ No. correct _____ [0 - 7] ☐

LANGUAGE

(a) Spontaneous speech
- fluency (phrases >5 words)
- paraphasic errors (phonemic or semantic)
- word finding difficulties

(b) Naming — Ask the patient to name the following pictures.
Record errors. [0 - 2] ☐

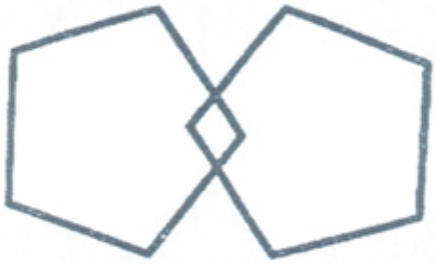


[0 - 10] ☐

(revised 2000)

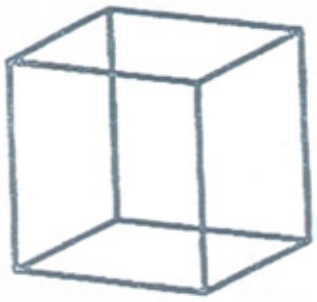
VISUOSPATIAL ABILITIES

(a) Overlapping pentagons Ask the patient to copy this diagram:



Score 1 if both figures have 5 sides and overlap. [0 - 1] ____

(b) Wire cube Ask the patient to copy this drawing:



Score 1 if correct. [0 - 1] ____

(c) Clock Ask the patient to draw a clockface with numbers and the hands at ten past five.

Score 1 each for correct circle, numbers and hands. [0 - 3] ____

CHECK: Have you tested and recorded the delayed recall time of name and address (page 1)?

OVERALL SCORES MMSE: ____/30 TOTAL: ____/100

Normative Study based on 127 subjects aged 50 to 80

Mean 93.9 ± 3.5 Cut off <87 for age 50–80

APPENDIX C

FAMILIARISATION OF EACH CASE STUDY – INTRODUCING THE INTERVIEWEES

The results of the first process of familiarisation of each case study are presented as vignettes below.

Case Study 1

S1 is a divorced 48 year old gentleman who had lost his job as a quality control manager and his family because of alcoholism. Afterwards, he had a spontaneous sub arachnoid haemorrhage due to an aneurysmal rupture. His brain injury required neurosurgical intervention and he spent 2 months in acute care. He was referred straight into community rehabilitation services and was then referred by the service to a vocational programme 2 years after his ABI. He obtained a job from his first placement at an advanced metal quality control laboratory. He advanced up the ranks rapidly despite an unsupportive supervisor but a very supportive manager. His current post is at a higher position than the last job he held before his injury. He has no problems whatsoever with alcohol as he is now teetotal. **Addenbroke's Cognitive Examination score was 93/100 (MMSE 29/30):** ACE revealed good orientation, verbal fluency, comprehension, reading, writing and visuospatial abilities. He has residual cognitive difficulties with memory and focussed attention. He requested and obtained a quiet office to help out with this and has not only sustained employment but been promoted.

F1 are his parents who have been a source of support to him and his children. They were his primary carers when he was in the initial stages of recovery and continue to watch his progress with pride.

E1 is a contemporary of his, an engineer, who was initially one of his supervisors and later a co-worker. He was appreciative of S1's interpersonal skills especially with his difficult supervisor and has had no previous knowledge or exposure to people with brain injury.

R1 was the social worker from the vocational programme with whom S1 had interacted. S1 had gained the respect and friendship of many members of the vocational rehabilitation team, not least R1, and has remained in contact with them.

Case Study 2

S2 is a 34 year old gentleman who had a traumatic brain injury. Before the injury and from the age of 14, he had been a key person in his parent's holiday business and worked from home. He was an expert skier and was very healthy at 18 - the time of his accident – resulting in a severe traumatic brain injury. After acute care and inpatient rehabilitation, he had been put in touch with a community Head Injury service, who had in turn put him in contact with a vocational programme where he had begun his course several years after his injury. He went through a placement in an old people's home and was so well liked that he was offered a job there. However he declined this offer but took up a winter job in a family friend's holiday business abroad. For the rest of the year he runs a lawn maintenance service, again working from home, largely supervised by his parents. He has major issues with memory, judgement and fatigue. **Addenbroke's Cognitive Examination score was 76/100 (MMSE 26/30).** ACE revealed a poor attention span and poor immediate and long term memory. Orientation, comprehension, reading and writing and visuospatial abilities were good while verbal fluency was moderate. He has insight into most of his problems. He has no residual physical difficulties. He has a dysarthria which worsens when he is fatigued but his speech is understandable. He has occasional problems with alcohol. Despite these difficulties, he has been able to keep both his jobs for around 3 years.

F2 are his parents who are very supportive but also very realistic of his abilities. They are not overprotective and are at present encouraging a move to independent living in a house financed with the compensation.

E2 is a very understanding and supportive employer who has found S2 a valuable asset to the business. He has personal experience with disability as a brother has had a disability all his life and had never worked. This has been a motivating factor in employing S2 and supporting him.

R2 was S2's job coach. A very outgoing job coach, she has been involved in his placement and has followed up events with the job that S2 chose for himself.

Case Study 3

S3 is a 25 year old gentleman who was knocked down while riding a bicycle. He was in his last year of school at that time and was thinking of a career as an air traffic controller. He sustained a bi-frontal injury and base of skull fracture. He was initially admitted under neurosurgery and then as an inpatient in a Neurorehabilitation Centre. He had very little physical impairment but significant memory and confabulation difficulties and poor insight. **Addenbroke's Cognitive Examination score was 81/100 (MMSE 29/30).** ACE revealed a poor immediate and long term memory, good orientation, attention, comprehension, reading, writing and verbal fluency but moderate visuospatial abilities. After rehabilitation, he went on to complete further education (CLAIT, RSA typing, a national diploma in IT application). He tends to consume alcohol regularly and cannot manage money very well. He started to attend Rehab UK and participated in 2 placements around 6 years after his accident before joining a large store on placement and successfully continues to work there.

F3 is his father who was a schoolteacher. F3 looked after S3 during the time of his prolonged inpatient stay and rehabilitation after the accident and continues to be a support. He arranged for S3 to live with his grandmother.

E3 is his personnel manager who has been responsible for sorting out several difficult events in S3's employment in the large store where he works. She has taken S3 under her wing and has often changed his postings when co-workers and managers have had difficulties. Perhaps from a personal understanding of disability, she has made several changes possible in the store, the last one being to have him "twinned" with another co-worker in a supervised role.

R3, the vocational programme's occupational psychologist, was S3's key worker. While she had not been involved with the placements, she and the job coach had followed S3 up closely through his multiple difficulties in the store – in close collaboration with E3.

Case Study 4

S4 is a 50 year old gentleman who was assaulted in his pub. He had required acute neurosurgical intervention and developed a recurrent right temporal abscess which required a Ventricular-Peritoneal shunt. He then spent a period of time in rehabilitation – initially as an inpatient in a Neurorehabilitation Centre and then with its community services. At this time, he also underwent several changes in his family, social and vocational spheres – going through a divorce, losing the family home and the pub he owned. **Addenbroke's Cognitive Examination score was 93/100 (MMSE 29/30).** ACE revealed a good orientation, memory, comprehension, reading, writing and visuospatial abilities. Verbal fluency was slightly affected. He was supported by social services initially and was then referred by the community service to a vocational rehabilitation programme where he started several years after his injury and went through a few placements but did not successfully hold down a job. He cannot drive as a result of a persisting visual field deficit. He lives alone and continues to require neurosurgical and

other interventions for recurrent illness. He worked as a volunteer cook helping homeless children and this then resulted in his first competitive paid employment in a hotel. He has not been able to sustain employment and has been through 3 jobs since then – all in hotels though he has never been unemployed for long. At the time of interview he was working as a night porter in a hotel. A few months later, he could not sustain that job due to illness.

F4, one of S4's daughters, with whom he still has a close relationship, had agreed on participating in the project. However after F4 visited her mother and other siblings, she changed her mind and dropped out of the study.

E4 was S4's line manager. She was the hotel manager of his last job (night porter). She was very supportive of S4 though she had no knowledge of his previous disability.

R4 was the vocational programme's social worker with whom S4 had interacted from the beginning of his time with the programme. S4 was one of the programme's first clients. R4 was one of the key staff in setting up the project at the time and had been involved with S4's community rehabilitation phase as well.

Case Study 5

S5 is a divorced 55 year old gentleman who had worked in a car body shop for 12 years. He was a workaholic, a hypertensive and had had a previous myocardial infarction 8 years prior to his stroke. He was a manager when he had a stroke (secondary to a right internal carotid artery occlusion) and was discharged from acute care settings back home as soon as he was stable. He went back to work as soon as he thought he was able and was found to have several cognitive difficulties which were exacerbated with fatigue. **Addenbroke's Cognitive Examination score was 90/100 (MMSE 30/30).** ACE revealed a moderate long term memory and visuospatial abilities, good orientation, immediate memory, attention, comprehension, reading, writing and verbal fluency.

Without his insight, previous personality traits interfered with his ability to function in his old managerial role and resulted in several interpersonal conflicts. His technical skills and his driving skills were affected after the stroke and were found to affect his work. His position was changed by his company in an attempt to accommodate him but two attempts to return to work failed. He was then referred by his company to a vocational rehabilitation programme around a year after his stroke. Work placements within his company as well as in 2 banks did not go well. His company did not take him back but provided him with ongoing financial support through their manager's insurance scheme. He does some voluntary work through the week, but feels that he has nothing to live for and is becoming increasingly unhealthy with increase in weight and alcohol use. Though he has is own home, he mostly stays with his aging parents. He feels abandoned by the company and the vocational programme.

F5, a bank manager, is S5's adopted daughter who is the only child who keeps in touch with him. After the stroke, the personality change, behavioural difficulties and his divorce, she supported him through his vocational rehabilitation and arranged for a placement in her own bank and realized the difficulties faced by S5 first hand.

E5 was S5's understudy at the body shop before the ABI. He took S5's job but after the initial mistrust, has remained friends with S5 who still comes in to talk occasionally. He has seen S5 at work before the ABI and afterwards as well. This wide perspective and keen observation made him a valuable source of information for S5's employment process.

R5 was S5's job coach. She took over from another job coach as a result of S5 having a complaint against the previous coach. However she managed to work alongside S5 through this difficult period but has not been able to maintain contact with him after the apparent abandonment of plans to return to work.

Case Study 6

S6 is a young gentleman, who had a motor bike accident in his early twenties. He had several injuries including a diffuse axonal brain injury with white matter contusions and was admitted under neurosurgery for around 5 months and was then an inpatient in a Neurorehabilitation programme. He continued as an outpatient and was referred to a vocational programme around 2 years after his injury. He has some limitation in hip range despite surgical excision of heterotopic ossification (extra bone deposition around joints). **Addenbroke's Cognitive Examination score was 79/100 (MMSE 29/30).** ACE revealed poor immediate and long term memory, good orientation, attention, comprehension, visuospatial abilities, reading, writing and verbal fluency. He has severe memory lapses, confabulation but has enough insight and uses Portable Digital Assistants and a Notebook Computer. He had been working with his father previously in a diamond drilling firm. After an unsuccessful placement as a volunteer driver (he would lose his way and forget what to do), he decided to do a vocational course which would lead to a job in a major car manufacturing company. Though he completed the course successfully, there were, unfortunately, no jobs available. He then lost contact with the vocational programme and felt he was discriminated because of his disability when applying for jobs. He continued to work with the Territorial Army and has obtained a heavy vehicle driver's license. He has gone through several jobs and at the time of interviews was in the process of leaving his job in a pub and joining as an assistant to an earth sampler.

F6 is a nurse, his girlfriend, who has, with his mother, supported S6 over the years and has been a job coach in many ways after he lost contact with the vocational programme.

E6 was the employer from his pub whom S6 promised would participate in the study. However, it became apparent that the brain injury had not been disclosed to E6. As it was likely that E6 might be contacted by the new employer for a previous reference, it was decided not to contact E6 as this might jeopardise references for S6's next job. This decision was jointly made by the researcher, his guides, vocational programme staff and

F6. It was put to S6, and retrospectively, he too felt that it might not be appropriate to include E6 in the study.

R6 is the vocational programme's Information Technology Supervisor who was S6's key worker. Unfortunately both S6's job coach and previous key worker had left the programme and R6 was the only person on the team who had been in contact with S6.

Case Study 7

S7 is a 39 year old office manager who sustained a left Middle Cerebral Artery stroke and was admitted for a brief period in acute stroke services before being discharged into the community without appropriate community referrals. She slowly recovered physically but continued to have fairly severe dysphasia, dyslexia and numerical memory difficulties and her personality changed. **Addenbroke's Cognitive Examination score was 64/100 (MMSE 27/30).** ACE revealed a poor immediate and long term memory, attention, grammar and verbal fluency but good orientation, comprehension, visuospatial abilities and writing. The Aphasia clinic at Newcastle University provided some support initially and then she was then started with the vocational programme around 2 years after the stroke. She was successfully placed and continues to work in the office of a major store and has been successful in compensating for her impairments.

F7 is her very supportive husband who gave up his job in the initial days to be her primary carer. As she went back to work, he would transport her to and fro till she could travel independently on the bus.

E7 was her supportive office manager who had allowed S7 to find her feet in the office at her own pace. E7 had a family member with disability and this not only helped her understand S7 better but also made her sensitive to the needs of the disabled at work. She was also a key person who was involved in making the store's national disability policy and was also involved in the execution of the policy.

R7 was S7's job coach. She continued to review S7's situation at work and later on in the employment had arranged for S7 to try and start using phones again in a simulated setting.

Case Study 8

S8 is a 23 year old gentleman who had a pedestrian- vehicle accident abroad. After initial acute care abroad, he returned to the UK and spent some time in an inpatient Neurorehabilitation programme before starting with a vocational programme around 4 years after his injury. He has minimal cognitive but no residual physical impairment. **Addenbroke's Cognitive Examination score was 85/100 (MMSE 27/30).** ACE revealed a fair immediate and long term memory, good attention, grammar and verbal fluency, good orientation (except time), good comprehension, visuospatial abilities and writing. He had no previous employment history as he had just finished school and had done GVNQs in Leisure and Tourism. He began a placement as a linen porter at a hotel belonging to a popular chain and slowly moved up the ladder to be the waiter of its restaurant. He stays with his parents. He found travelling to and from work difficult. However his job became untenable as his co-worker turned line manager became very difficult to work with. He then resigned as he had another job in place in another restaurant as a waiter but this new job did not suit him and he had spent several months looking for other similar jobs.

F8 is S8's father. He is a businessman who is keen for S8 to take up a more challenging job and disapproves of his long period of current unemployment. He feels the financial security from the compensation has been a disincentive. He also feels that the loss of S8's first job is not related to the fact of the brain injury.

E8 was the supportive co-worker turned supervisor who was the stated reason for the S8's resignation. E8 actually agreed to an interview but on the day of the interview felt that he needed company approval which was subsequently not given for taped interviews.

R8 was the vocational programme's Information Technology supervisor who was, unfortunately, the only member of the team left from S8's time there and only had contact with him for IT sessions.

APPENDIX D

PUBLICATION

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24

Vocational rehabilitation

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Introduction

This chapter will discuss the principles, process, and practice of vocational rehabilitation in stroke. The definition of vocational rehabilitation is introduced because this has implication on the width of its endeavour.

The word vocation is often used to specify a profession or trade. But vocation also means choice of a life's career and a predisposition to a particular calling. Vocational rehabilitation is, therefore, more than just getting a person back to work. It is integrally woven into an attempt to bring back choices into a person's life. It often is the person's way back to his or her calling and life work. It is a route for a person with disability to gain back a right to give to society.

Vocational rehabilitation is defined as the attempt to maximize vocational potential and function. Rehabilitation is an approach to maximize physical, psychological, and social function of people with disability. There are three levels at which rehabilitation attempts to maximize function: impairment, activity (disability) and participation (handicap). Rehabilitation attempts to:

- alleviate impairment or actual loss of function
- improve activity that has been restricted by the impairment (i.e. it attempts to reduce disability)
- enable participation in a social role unfulfilled as a result of disability (i.e. it attempts to reduce handicap).

Vocational rehabilitation would need to address vocational needs at the three levels of impairment, activity, and participation.

The discussion will draw on evidence from research on vocational rehabilitation in traumatic brain injury as there is little published on stroke. There is a reasonable amount of information available from similar, relevant research in traumatic brain injury. It could be argued that brain injury following stroke is different from brain injury following trauma. Comparatively, people with stroke might have more focal and less-diffuse frontotemporal injury, resulting in fewer cognitive and

Recovery after Stroke, ed. Michael P. Barnes, Bruce H. Dobkin and Julien Bogousslavsky. Published by Cambridge University Press.

more motor sequelae. In addition, people with stroke are generally older, closer to retirement, and would, therefore, face different expectations surrounding their return to work at full capacity. However, the causative factors and sequelae are similar in any brain injury and vocational rehabilitation programs talk about "acquired brain injury" and include both groups in their programs. Consequently, evidence will be drawn from research on vocational rehabilitation in traumatic brain injury.

Do those with stroke need vocational rehabilitation?

There is a small group of people with stroke who are affected during their vocational lives and need to maximize residual vocational potentials. In 1975, a Swedish study estimated the size of this group to be approximately 28 per 100 000. It also estimated that approximately 4–5 per 100 000 could be actively reemployed (Fugl-Meyer *et al.*, 1975). Approximately 15–20% of all people with stroke are of working age; approximately 41% return to work and 21% try and fail to return to work (Heinemann *et al.*, 1987; Vestling *et al.*, 2003). Therefore, there is obviously a group of people with stroke who would need vocational rehabilitation. In addition, though the size of this group may be small, as the age of retirement increases, the numbers of people with stroke who are still working will obviously increase (Wozniak *et al.*, 1999). Consequently, the numbers with stroke needing to return to their vocations is going to increase.

Principles of vocational rehabilitation

Basis in a partnership model

In a broad sense, the available models of rehabilitation are the medical and social models. The medical model of vocational rehabilitation focuses on addressing the difficulties in the person with disability while the social model focuses on addressing the social aspects creating difficulties for the person with disability. As in other areas of rehabilitation, the World Health Organization (WHO) suggest that both models will need to work together using a "biopsychosocial" approach in order to get people with stroke back to work (WHO, 2001). This has been called the partnership model (Barnes and Ward, 2000).

Requirement for personal empowerment

One of the principles of rehabilitation is empowerment. This means that the power and control of decisions are handed over to the person with disability. This is especially important in vocational rehabilitation as empowerment can positively influence motivation. When choosing life's career or deciding on a calling, the long-term

results are always better when the individual has the freedom to choose from the options that the vocational rehabilitation program lays out (Brooke *et al.*, 2003).

Requirement for continuing support

Traditional vocational rehabilitation approaches have been limited to preplacement evaluations and interventions based on these evaluations. Both evaluation and interventions were provided in medical settings and their effects were expected to be transferred or generalized to real-life situations at work. These traditional services were generally provided by adult day centers, sheltered workshops, or segregated institutions (Fraser *et al.*, 1997). Not surprisingly, these approaches have reported disappointing results. Return to work was less than 40% in a day-care program (Haffey and Abrams, 1991) and averaged in the range 20–50% (Ip *et al.*, 1995; Greenspan *et al.*, 1996; Sander *et al.*, 1996; Cattelani *et al.*, 2002).

However, in the 1980s, two vocational program models evolved: the work reentry program (Haffey and Abrams, 1991) and the supported employment program (Wehman *et al.*, 1990). The basic principle of both was to provide continuing support. These programs, like their older counterparts, provided preplacement support and evaluation. However, in addition, they began to guide clients through specific job situations in actual work environments with the help of a "job coach." The programs continued follow-up and support, even after actual employment, through the job coaches. In addition the job coaches were involved in developing natural supports in the workplace; coworkers became mentors and technological supports were brought into the workplace to enable employment to be sustained. Both the work reentry program and the supported employment program are very similar in approach and results and, therefore, no attempt is made to differentiate between them. Not surprisingly, their results are superior to previous approaches. The supported employment approach has resulted in an encouraging return to work of 77% (Dean *et al.*, 2003). The work reentry program reports a 71% employment retention rate (Haffey and Abrams, 1991), resulting in increased governmental support. It has been felt that rehabilitation stopped too early. After stroke, people felt unprepared and wished for continued vocational rehabilitation support (Lock *et al.*, 2005).

Guiding values in vocational rehabilitation

The partnership model of vocational rehabilitation will need to address the needs of the individual as well as societal responses. This means that a common set of guiding values need to be identified that help in setting the goals of a vocational rehabilitation program.

The Department of Physical Medicine and Rehabilitation of the Medical School of the University of Virginia were instrumental in developing the supported

Table 24.1 Guiding values of a supported employment program

Value	Definition
Presumption of employment	Everyone, regardless of the level or the type of disability, has the capability and right to a job
Competitive employment	Employment occurs within the local labor market in regular community businesses
Control	When people with disabilities choose and regulate their own employment supports and services, career satisfaction will result
Commensurate wages and benefits	People with disabilities should earn wages and benefits equal to those of coworkers performing the same or similar jobs
Focus on capacity and capabilities	People with disabilities should be viewed in terms of their abilities, strengths, and interests rather than their disabilities
Importance of relationships	Community relationships both at and away from work lead to mutual respect and acceptance
Power of supports	People with disabilities need to determine their personal goals and receive assistance in assembling the supports necessary to achieve their ambitions
Systems change	Traditional systems must be changed to ensure customer control, which is vital to the integrity of supported employment
Importance of community	People need to be connected to the formal and informal networks of a community for acceptance, growth, and development

From the program of the Deptment of Physical Medicine and Rehabilitation, Medical School of the University of Virginia, USA (Brooke *et al.*, 2003).

employment program. They now are involved in training and have published excellent manual that outlines the basics of the program in which they sugge number of guiding values or principles (Brooke *et al.*, 2003; Table 24.1).

The process of vocational rehabilitation

The description here of the process of rehabilitation is divided into two m sections. The first section deals with the selection process, discussing the fac

that are important in successful rehabilitation. The next section deals with the actual phases of a successful program.

Selection: which factors are associated with better return to work?

The list of factors associated with successful return to work is more important from the point of view of providing prognostic information to the client. The factors outlined should not be selection or exclusion criteria to a vocational rehabilitation program. Except for purposes of research, water-tight selection or exclusion criteria in a vocational rehabilitation program can often mislead the team and exclude potential successes.

It must be remembered that these criteria are based on relatively weak statistical evidence and can only shed light on the path; they cannot be the path itself. There have been no randomized control trials as attempts to form control groups have failed. Moreover, more than three quarters of failures in vocational rehabilitation occur for multiple reasons. Existing research reports a very wide variation: the percentage of people with stroke returning to work ranges from 21 to 73% (Wozniak *et al.*, 1999). There is a wide variation in results, probably because research in this field has yet to address the following methodological needs:

- sharper definition of temporal categories (acuteness of stroke)
- standardization of diagnostic categories of stroke
- standardization of vocational rehabilitation approaches
- long-term follow up data.

However weak the existing data, it is important for both the person with disability and the service provider to enter the process of vocational rehabilitation with clear sightedly. There are physical and psychosocial factors associated with success or failure in returning to work.

Physical factors

While most people with stroke returning to work will be younger than 65 years, the probability of returning to work decreases once the stroke survivor is past 55 years of age (Wozniak *et al.*, 1999). A corollary, however, is that individuals with brain injury in their late twenties are more difficult to place than those in their late thirties (Ponsford, 1995).

A higher level of function, as indicated by the Barthel Index, was also positively associated with return to work (Wozniak *et al.*, 1999).

Return to work does not seem to be affected by the extent of physical disability: aphasia level of consciousness and weakness at the time of the stroke, severity of stroke, race, sex, and pre-existing depression did not affect return to work significantly (Howard *et al.*, 1985; Wozniak *et al.*, 1999). There was no difference between right- and left-sided strokes. Neither was there any difference in return to

work associated with race or with cortical, infratentorial, or lacunar strokes (Wozniak *et al.*, 1999) though fatigue was reported to be a problem (Lock *et al.*, 2005). However, the absence of either weakness or apraxia was identified as being predictive of return to work (Saeki *et al.*, 1995) as was preserved cognition and ability to walk (Vestling *et al.*, 2003).

Psychosocial factors

The case for psychosocial factors is much stronger than for physical factors.

Type of job

Return to work was shown to be better with white collar jobs rather than blue collar jobs (Howard *et al.*, 1985; Saeki *et al.*, 1995; Vestling *et al.*, 2003). A strong pre-injury work history was a strong predictor of return to work (Heinemann *et al.*, 1987). However, a client returning to a highly skilled job or work reentry at a lower level than the premorbid job are associated with poor outcomes (Heinemann *et al.*, 1987).

Economic disincentives

An income of more that US$30 000 annually was a positive predictor of return to work (Wozniak *et al.*, 1999). The time at which return to work seemed to peak appeared to be associated with the period allowed by social security: around 18 months in a Japanese study (Saeki *et al.*, 1995). It was also noticed that the reason why 6 of 25 clients with brain injury did not return to work was because the disability or compensation incomes were in excess of the potential earned income (Haffey and Abrams, 1991).

Substance abuse

Substance abuse is a strongly negative factor that emerges in almost every study at some point (Abrams *et al.*, 1991; Sale *et al.*, 1991; Ponsford, 1995). In around a third of clients who could not keep their jobs, substance abuse or criminal activity contributed to job separation (Sale *et al.*, 1991). This factor is so important that many vocational programs now exclude those with continuing problems with substance abuse.

Attitude to injury

Clients with a sense of responsibility did much better than those with a sense of victimization regarding the injury (Abrams *et al.*, 1991).

Interpersonal relationships

Factors relating to interpersonal relationships were reported to be responsible for around half of the job separations, including misinterpretation of social cues, interpersonal conflict, and inappropriate verbalization (Sale *et al.*, 1991).

Work-related skills

Skills such as initiating a task without prompting or direction, responding to non-verbal cues, observing safety requirements and using compensatory strategies consistently are important. Their absence makes it difficult for a person to return to work (Fraser *et al.*, 1997).

Family support

Strong family support is a useful predictor of successful return to work (Abrams *et al.*, 1991).

Phases of a supported employment program

The supported employment model would take a client through three phases: initial assessment, job placement, and long-term support and follow-up

Initial assessment

The first phase is the assessment and planning, which is focused on individual work-based skills and environmental opportunities and responses. The neuropsychological, medical, and social abilities of the client are perceived from this viewpoint. While test batteries and specialist scales are useful, none comprehensively discover all the needs or identify all the vocational potentials of a client (Tyerman, 1999a).

The individual's abilities in areas of functional independence, mobility, transfers, transportation, cognition, executive function, behavior, stress management, and safety cannot be assumed but must be tested and observed. Neurobehavioral aspects will be of special importance as motivation, behavior, and interpersonal relationships play an important role in maintaining employment. Abilities will need to be matched with felt needs. After abilities and felt needs are matched, the individual and the team sit down together to agree on goals and time frames. Progress along the agreed pathway will need follow-up and modification depending on the evolving situation.

Once the individual's ability and work-based skills are known, assessments for environmental opportunities will need to be carried out. This includes assessing skills required for the job development processes, for example preparing a resume, business interview skills, and phone conversations, including "cold calls" to employers.

The process of exploring environmental responses will need assessment. This includes identifying potential employers with whom the individual could undertake a placement. The pre-existing organizational marketing infrastructure and community networks of the rehabilitation service provider will come into play here. The employer or organization identified will need a SWOT (strength, weakness, opportunities, threats) analysis specific to the individual whose placement

is planned. The rehabilitation service provider markets the individual and the individual's skills to employers within the network. It is often the case that employers actually benefit from the experience as they have work done in an environment of evaluation and support and have the opportunity to continue or stop the experience at the end of six weeks without any financial or legal implications. Assessment of environmental responses will also involve assessment and development of work-related family support.

This process can last for 6 to 12 weeks.

Job placement

The next phase is the placement and training. The job coach plays a central role from this point. Appropriate options are chosen in the light of the assessment and performance and evaluated. This process continues till a satisfactory result is obtained.

There are several models of placement, such as the traditional job clubs or job call lines, selective placement by the agency acting as a broker, the more active agency-generated job site support, and the proactive natural support in the workplace (training a coworker to be a mentor) (Fraser *et al.*, 1997).

During job placement, the assessment continues with job duty analysis both by the individual and by the employer. Assessment and development of natural supports in the work place might need to be supplemented with natural cues or extra cues that (a cue being a feature that would indicate to the individual what to do next). If cues are insufficient, verbal or gestural prompts may need to be introduced. Once cues are successfully instituted, fading of cues or prompts will need assessment. Other compensatory aids like imagery, mnemonics, a reminder notebook or whiteboard, and rehearsals might need to be instituted.

Again this could last anywhere from six weeks to six months.

Job support and long-term follow-up

The final phase is job seeking and continued support. The issue of job stability in brain injury is addressed by continued support at work and retraining when necessary. This support is usually offered for five years, though it might basically be a lifelong process.

Once back at work, persons with brain injury are challenged with being able to sustain a job. With the traditional approaches, 30–50% of those who returned to work could not sustain their jobs (Ip *et al.*, 1995; Greenspan *et al.*, 1996; Sander *et al.*, 1996; Cattelani *et al.*, 2002). Though a significantly larger percentage of people with stroke return to work with the supported employment approach, job stability seems to remain a problem with almost the same proportion of people (around 26%) requiring a second placement (Wehman *et al.*, 1995). Approximately 69% of

those with job separations lose their jobs in the first six months (Sale *et al.*, 1991). This is such a common feature on vocational rehabilitation that it has been coined the "return loop syndrome" (Parenté *et al.*, 1991).

The return loop syndrome is characterized by successfully coached clients returning to the vocational program within a five-year period having either left or lost their jobs. The usual reasons for this are multiple and, apart from the factors mentioned above, include:

- upward mobility: after successful return to work and improved self-esteem, the client feels confident of taking up jobs with either increasing demands or poorly matching with their abilities; in addition, they do not put compensatory strategies into place
- change in job duties: a client who is able to stay with a job starts to experience change in environment, demands, managers, or coworkers; these changes cause stress and challenge coping abilities
- loss of support system: as the client becomes more engrossed in the vocational environment and the job coaching contact is slowly withdrawn by the program, contact and support of the peer interaction, therapy sessions, and feedback is lost.

There have been several approaches to prevent the return loop syndrome. The sense of loss of support could be countered by keeping follow-up open ended. The follow-up team could be more flexible and offer more intervention based on appropriate follow-up. This would mean that job coaches would need to be trained in trouble-shooting and crisis management skills (Parenté *et al.*, 1991). Employee assistance programs will need to be developed. Peer interaction sessions could be continued and hopefully these would address more than just vocational needs. Natural supports will need to be developed at the work place. This might include training, supporting, and advising, coworkers or employers to act in a mentors' role to improve job stability.

Putting principles and processes into practice

This section briefly describes some of the approaches used to deliver vocational rehabilitation services.

Provision of internal and external supports

There are various ways of supporting the values of supported employment and these can be broadly classified into internal supports (processes that people with disability train to use themselves) and external supports processes instituted in or on the surrounding environment (Table 24.2; Brooke *et al.*, 2003).

Table 24.2 Provision of internal and external support

Area of need	Internal supports	External supports
Capacity and capabilities	Physical enablement; cognitive enablement (e.g. initiation, dyspraxia, insight); behavioral enablement (e.g. coping skills for anger, stubbornness, consistency)	Education; control of substance abuse
Presumption of employment, competitive employment, control, commensurate wages and benefits	Develop self-image; develop motivation; education on rights, privileges and opportunities	Financial aid; modify level of responsibilities; adapt job environment
Power of supports and systems change		Specific vocational training; compensation; assistive technology; networking
Importance of relationships and importance of community	Positive family support: interdependent rather than dependent or undependable	Social, peer, and employer support; coworker (twinning) support

Customer-driven approach to supported employment

The Virginia University Manual suggests a customer-driven practice to enable the program to remain faithful to its principles (Brooke *et al.*, 2003).

1. Choice: the "customer–client" makes the informed choice, not the service provider.
2. Control: the "customer–employee" is the coordinator of the job with the employer, not the rehabilitation professional.
3. Careers: career development is built into the job and it cannot be assumed that the job obtained will be a dead end.
4. Full inclusion: there should be no discrimination, positive or negative, at the work place.
5. Long-term support: coworkers as much as job coaches can help to sustain employment.

6. Community and business supports: networking.
7. Total quality management: interaction and feedback from the client can improve the rehabilitation program.
8. Assistive technology: environmental engineering (ergonomic placement of commonly used articles, color-coded documents, cue cards at appropriate places), prosthetic memory aids (tele-memo watches, diaries, phones with number memories, dictaphones), and cognitive orthotic devices (spell check or word-finding software) (Parenté *et al.*, 1991).
9. Person-centered planning.

The job coach

The key to putting these principles and processes into practice is the job coach, who is the primary service provider in this approach. The Virginia University group have a fairly broad definition of the job coach, who has alternatively been called trainer advocate, job trainer, supported employment training specialist or employment specialist.

It is obvious that the job coach will need a host of skills deriving from various walks of life: psychology, counselling, education, marketing, and business (Brooke *et al.*, 2003). It might not be possible to find or train one person to fulfill all these functions and, therefore, several roles have been identified that could be fulfilled by one person or by various members of a vocational rehabilitation team. There are five distinct roles that job coaches perform.

1. Planner role: assess the client (customer profiling), assessing various job sites to match them with the client (resource matching), and training the client for interviews (resumes, cards, handling phones) using the person-centered planning approach.
2. Consultant role: provide recommendations to the client to get and keep a job.
3. Head hunter role: organizational marketing (building and maintaining a network of job providers), market and employer surveys, and matching client and job provider using a market-based planning approach.
4. Technician role: provide rehabilitation solutions for problems with transfers, cognitive dysfunction, and other disabilities at the work site. Suggest assistive technologies and develop natural supports at the work site.
5. Community resource role: networking and creative linking; fading from the job site neither too slowly (creates dependence) nor too fast (results in job losses).

Therefore, the function of the job coach would be customer profiling, career development, employment matching, job-site training and support, and provision of long-term support and extended follow-up.

Are vocational rehabilitation models beneficial?

Evaluating the efficacy of the supported employment and work reentry programs with a randomized double–blind control trial has not been possible, primarily because of the ethical difficulties of withholding vocational services to a control group.

However, the viability of modern vocational programs has been supported by cost–benefit analysis studies returned to the government funding agencies. This was done using comparison rather than control groups for 4000 clients in one state in the USA, comparing longitudinal incomes and service costs. The results were encouraging. The economic viability of the supported employment approach has been similarly demonstrated with qualitative and economic variables in small groups (Ponsford, 1995; Dean *et al.*, 2003). One recent 14-year longitudunal study reporting individual earnings of US$175 15 more than the costs associated with the individual's supported employment placement (Wehman *et al.*, 2003). A UK vocational rehabilitation project reported that, if savings in benefits and tax revenues as a result of return to work were calculated, the pay-back period to cover vocational rehabilitation costs was 21.6 months. They reported that, in their project, net savings to the exchequer were accumulating over three years at a rate of £300 per month (Tyerman, 1999b).

The improved percentages of those returning to work with supported employment or work reentry programs are the other soft evidence that vocational rehabilitation programs are beneficial, but there is a need for further, more robust research in this area.

Summary

Vocational rehabilitation would benefit around 15% of those who survive stroke beyond a year. The factors that influence return to work are more psychosocial than physical and, therefore, approaches need to include both medical and social aspects (partnership model). To empower the person with disability, the vocational rehabilitation program needs to be customer driven.

The supported employment and work reentry programs have reported more successful outcomes than previous approaches, probably because they provide continued support. They not only provide initial evaluation and counselling but also continue with ongoing evaluation and advice at job placements and follow-up and support through employment. The role of the job coach is the key to a successful supported employment program. However, people with disability continue to have problems with maintaining stable employment (return loop syndrome). The same factors that affect return to work continue to play a role in poor job stability.

Results are encouraging, with around 70% of clients in supported employment and work reentry programs returning to work, but there are methodological difficulties in obtaining controls for further research. Though largely reported for acquired brain injury in general, rather than stroke in particular, cost–benefit analyses of vocational rehabilitation projects are encouraging and evidenced by further governmental involvement in these programs.

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